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ABSTRACT

This theme issue newsletter presents six brief articles on sexuality education for children and youth with disabilities. Each article presents an overview of important points to consider when providing sexuality education, then concludes with a list of materials for families and professionals. The first article, "The Development of Sexuality," presents essential information on sexuality and sexuality education. The second article, titled "The Importance of Developing Social Skills," offers parents suggestions in promoting their children's socialization skills. Next, "Teaching Children and Youth about Sexuality" offers suggested discussion topics by age group (preschool through adolescence). The fourth article is primarily a bibliography of resources (grouped by disability) concerned with "How Particular Disabilities Affect Sexuality and Sexuality Education". The next article briefly addresses "Fostering Relationships: Suggestions for Young Adults". The final article offers resources on special issues including sexual orientation, reproduction and birth control, protection against sexually transmitted diseases, and protection against sexual exploitation and abuse. (DB)

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ED 346676

Sexuality Education for Children and Youth With Disabilities

NICHCY News Digest

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National Information Center for Children and Youth with Disabilities
Washington, DC

Today, due to the work of advocates and people with disabilities over the past half-century, American society is acknowledging that people with disabilities have the same rights as other citizens to contribute to and benefit from our society. This includes the right to education, employment, self-determination, and independence. We are also coming to recognize —albeit more slowly— that persons with disabilities have the right to experience and fulfill an important aspect of their individuality, namely, their sexuality. As with all rights, this right brings with it responsibilities, not only for the person with a disability but also for that individual's parents and caregivers. Adequately preparing a child for the eventuality of adulthood, with its many choices and responsibilities, is certainly one of the greatest challenges that parents face.

Each year hundreds of families and professionals contact NICHCY with questions about the social-sexual development of children with disabilities and how to contribute positively to the growth of their children in this area. This NEWS DIGEST has been developed to address the concerns that parents and professionals face in informing and guiding children and young adults with disabilities in their social-sexual development and in preparing them to make healthy, responsible decisions about adult relationships. Because of the complex nature of the subject matter, this NEWS DIGEST has been organized in a different way from other issues. It is intended to serve largely as a resource document, pointing parents and professionals to many of the excellent books and videos on human sexuality that are available. When providing education about the development and expression of sexuality, there is no substitute for the detailed illustrations and discussions that many of these books contain. Each of the sections in this NEWS DIGEST presents an overview of important points to consider when providing sexuality education, then concludes with an extensive list of materials that families and professionals can use to inform themselves more fully. These materials can also be used to facilitate discussions with children and youth about sexuality. In this way, families and professionals can address the unique needs of the youth with whom they are working, while also approaching sexuality education in ways that reflect the deeply personal beliefs that they may hold in regards to these matters.

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Some Quotes From Parents

"My daughter's 13 and she's taking sex ed at school. She came home yesterday and started asking me questions. She'd seen a movie in class and hadn't really understood it—it went too fast, and she was too embarrassed to ask questions. So we sat down and I explained in real basic terms and showed her a few pictures from the encyclopedia. I never thought that having a learning disability was going to make it hard for her to learn about sexuality. And it also made me think of my own mother telling me about sex when I was 10 or so. I wonder if my mother felt as awkward talking to me as I felt talking to my daughter. Probably."

"I remember the day my father explained to me about getting a woman pregnant. I didn't understand it all, but I sure understood his point: Be careful! I told my son the same thing, but we both knew it was unlikely. He killed me when he said, But Dad, no girl's gonna want to go out with me."

"When my daughter got her period, I don't know which I felt more — terrified or proud. This means she's turning into a woman. And that means she can get pregnant. I go back and forth on it. Since she's mentally retarded, it's been hard to teach her about caring for herself when she has her period, but now she's so proud that she can manage mostly without my help. I wish that were all she had to learn about taking care of herself in this world!"

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THE DEVELOPMENT OF SEXUALITY

The natural course of human development means that, at some point in time, children will assume responsibility for their own lives, including their bodies. As the above quotes from parents show, parents face this inescapable fact with powerful and often conflicting emotions: pride, alarm, nostalgia, disquiet, outright trepidation, and the bittersweetness of realizing their child soon will not be a child anymore. Indisputably, the role that parents play in their child's social-sexual development is a unique and crucial one. Through daily words and actions, and through what they *don't* say or do, parents and caregivers teach children the fundamentals of life: the meaning of love, human contact and interaction, friendship, fear, anger, laughter, kindness, self-assertiveness, and so on. Considering all that parents teach their children, it is not surprising that parents become their children's primary educators about values, morals, and sexuality.

For many reasons, some personal and some societal, parents often find sexuality a difficult subject to approach. Discussing sexuality with one's child may make parents uncomfortable, regardless of whether their child has a disability or not, and regardless of their own culture, educational background, religious affiliation, beliefs, or life experiences. For many of us, the word sexuality conjures up so many thoughts, both good (joy, family, warmth, pleasure, love) and fearful (sexually transmitted diseases, exploitation, unwanted pregnancies). For parents with children who have disabilities, anxieties and misgivings are often heightened.

Unfortunately, there are many misconceptions about the sexuality of children with disabilities. The most common myth is that children and youth with disabilities are asexual and consequently do not need education about their sexuality. The truth is that all children are social and sexual beings from the day they are born (Sugar, 1990). They grow and become adolescents with physically maturing bodies and a host of emerging social and sexual feelings and needs. This is true for the vast majority of young people, including those with disabilities. Many people also think that individuals with disabilities will not marry or have children, so they have no need to learn about sexuality. This is not true either. With increased realization of their rights, more independence and self-sufficiency, people with disabilities are choosing to marry and/or become sexually involved. As a consequence of increased choice and wider opportunity, children and youth with disabilities *do* have a genuine need to learn about sexuality–what sexuality is, its meaning in adolescent and adult life, and the responsibilities that go along with exploring and experiencing one's own sexuality. They need information about values, morals, and the subtleties of friendship, dating, love, and intimacy. They also need to know how to protect themselves against unwanted pregnancies, sexually transmitted diseases, and sexual exploitation.

What Is Sexuality?

According to the Sex Information and Education Council of the U.S. (SIECUS):

> Human sexuality encompasses the sexual knowledge, beliefs, attitudes, values, and behaviors of individuals. It deals with the anatomy, physiology, and biochemistry of the sexual response system; with roles, identity, and personality; with individual thoughts, feelings, behaviors, and relationships. It addresses ethical, spiritual, and moral concerns, and group and cultural variations. (Haffner, 1990, p. 28)

One of the primary misconceptions that society holds about human sexuality is that it means the drive to have sexual intercourse. While this may be part of the truth regarding sexuality, it is not the whole truth. As the above statement shows, human sexuality has many facets. Having a physical sexual relationship may be one facet of our sexuality, but it is not the only one or even the most compelling or important. Sexuality is, in fact, very much a *social* phenomenon (Way, 1982), in that all of us are social creatures who seek and enjoy "friendship, warmth, approval, affection, and social outlets" (Edwards & Elkins, 1988, p. 7). Thus, a person's sexuality cannot be separated from his or her social development, beliefs, attitudes, values, self-concept, and self-esteem. Being accepted and liked, displaying affection and receiving affection, feeling that we are worthwhile individuals, doing what we can to look or feel attractive, having a friend to share our thoughts and experiences — these are among the deepest human needs. Our sexuality is intimately connected with these needs. Thus, our sexuality extends far beyond the physical sensations or drives that our bodies experience. It is also what we feel about ourselves, whether we like ourselves, our understanding of ourselves as men and women, and what we feel we have to share with others.

How Does Sexuality Develop?

An understanding of sexuality begins with looking at how the social and sexual

Some people assume that if you are disabled, you can't have a social life or a sex life. This reflects one's own fears that unless one looks terrific physically, he or she will not be wanted. This is very potent stuff.

We are all desirable; each of us has sexual potential. It is part of us someplace, somewhere. There is opportunity –it is not easy, but there is potential–if you look for it. We are all sexual by definition; it is part of our existence. **(Karen M., in Weiner, 1986, p. 72. Copyright (c) 1986 by Florence Weiner. From the book *No Apologies*.)**

All quotes from *No Apologies* reprinted with permission from St. Martin's Press, Inc., New York, New York.

self develops. These two facets of the total self must be examined in conjunction with one another, for sexuality is not something that develops in isolation from other aspects of identity (Edwards & Elkins, 1988). Indeed, much of what is appropriate sexual behavior is appropriate *social* behavior and involves learning to behave in socially acceptable ways.

From the time we are born, we are sexual beings, deriving enormous satisfaction from our own bodies and from our interactions with others, particularly the warm embraces of our mother and father. Most infants delight in being stroked, rocked, held, and touched. Research shows that the amount of intimate and loving care we receive as infants "is essential to the development of healthy human sexuality" (Gardner, 1986, p. 45). The tenderness and love babies receive during this period contribute to their ability to trust and to eventually receive and display tenderness and affection.

The lessons learned during the toddler stage are also important to healthy social-sexual development. Toddlers receive pleasure from others and from their own bodies as well. The uninhibited pleasure that toddlers derive from exploring their own bodies is sometimes regarded with humor and at other times with embarrassment. If these self-exploratory activities are accepted by the adults around them, children have a better basis from which to enjoy their bodies and accept themselves. This does not mean that adults around a toddler should refrain from distracting the child from some behaviors in inappropriate situations, or not impress upon him or her that there are appropriate and inappropriate environments for self-exploration. However, experts do advise against excessive adult reactions that indicate such behaviors are "bad," because such reactions communicate that the body is "bad" or "shameful" (Calderone & Johnson, 1990).

All people can love, and all people can make human contact with other people.
(Hingsburger, 1990, Preface)

We form many of our ideas about life, affection, and relationships from our early observations. These ideas may last a lifetime, influencing how we view ourselves and interact with others. Because children are great imitators of the behaviors they observe, the environment of the home forms the foundation for their reactions and expectations in social situations. Some homes are warm, and affection is freely expressed through hugs and kisses. In other homes, people are more formal, and family members may seldom touch. The amount of humor, conversation, and interaction between various family members also differs from home to home. Some families share their deep feelings, while others do not. Children observe and absorb these early lessons about human interaction, and much of their later behaviors and expectations may reflect what they have seen those closest to them say or do.

"From the time we are born, we are sexual beings, deriving enormous satisfaction from our bodies and from our interactions with others..."

In the preschool and early school years, most children become less absorbed with self-exploration but maintain their curiosity about how things happen. They may disconcert parents by suddenly and directly asking simple (and not so simple!) questions about sexual matters. They are also fascinated to discover that the bodies of opposite-gender playmates are different from their own, and may investigate this fact through staring, touching, or asking questions. This type of behavior is normal and needs to be treated as such. It may help parents to realize that children's curiosity about and exploration of the body are natural evolutions in their learning about the world and themselves. Strong, emotionally-laden reactions on the part of parents can be damaging to children, in that they can learn to feel guilt or shame about their body parts (Tharinger, 1987). Answering questions calmly and truthfully, and displaying a certain degree of leniency regarding children's curiosity will help them develop a positive attitude about their bodies.

Children are learning other things about themselves at this time as well. They begin to play with their peers now, where previously they played next to them but separately. They also begin to test themselves in the social environment: They hit, take toys, and commit other anti-social acts. They make many mistakes, are corrected, and learn necessary lessons about acceptable behavior. These interactions and the lessons learned are important to their concept of self within society.

During this time period, children are also consolidating ideas about gender and gender roles, or what it means to be a male or a female. Between the ages of two and three, most children develop a sure knowledge that they are male or female. By age five, most are well on their way to understanding the kinds of behaviors and attitudes that go with being female or male in this society (Calderone & Johnson, 1990). They form concepts about gender identity by observing the activities of their parents and other adults, and through what others expect or ask them to do. Gender messages are sent to children in many forms. Early messages teach children what gender they are. Then as children grow, messages begin to relate to what type of behavior is appropriate for each gender. The type of toys children are given for play, the clothes they may wear, the type of activities they are permitted to pursue, and what they see their parents doing send nonverbal messages about gender. Voiced expectations contribute as well; some examples are "Be a brave little boy! Brave boys don't cry" and "When you go to the bathroom, you stand up like Daddy/sit down like Mommy." Through such statements and expectations, and through observing the actions of adults, children learn about gender roles and behaviors, and they pattern their behaviors accordingly (Calderone & Johnson, 1990).

In the early school years, the curiosity and explorations of early childhood give way for many children to a period in which

> ***Socially, the most painful time for me was when I was a teenager. As a young adolescent, even when I was feeling kind of good about myself, looking nice, I'd still walk out and think, No matter how nice I look, I still walk funny. Well, that's life. Or if I was walking down the street, feeling good, and someone laughed at me, that was a real downer. It is very painful, particularly when you're a teenager, struggling so much with what you feel about yourself, your desirability, your attractiveness.***
> (Karen M., in Weiner, 1986, p. 72)

interest in the other gender may lessen in favor of new interests and relationships. It is not unusual for some children to reject members of the opposite gender during this period, especially when in the presence of members of the same gender. Some even scorn association with the opposite gender. But this is by no means universally true. Tharinger (1987) cites a number of studies that support the claim that, far from being sexually latent, many children during this age "discuss sex-related topics frequently and others show keen interest in the opposite sex, desiring to be in the presence of the opposite sex, and under certain circumstances may engage in activities with members of the opposite sex" (pp. 535-6). Both of these reactions — rejecting the opposite gender or showing an interest in the opposite gender — are normal, for during the early school years children are learning about themselves as boys or girls. Friendships, playmates, games, and activities are important during this period to the continuing development of the sense of self within a social sphere.

With puberty, which starts between the ages of 9 and 13, children begin to undergo great physical change brought about by changes in hormonal balance (Dacey, 1986). Both sexes exhibit rapid skeletal growth. Physical changes are usually accompanied by a heightened sexual drive and some emotional upheaval due to self-consciousness and uncertainty as to what all the changes mean. Before the changes actually begin, it is important that parents talk calmly with their children about what lies ahead. This is a most important time for youth; many are filled with extreme sensitivity, self-consciousness, and feelings of inadequacy regarding their physical and social self. Indeed, their bodies are changing, sometimes daily, displaying concrete evidence of their femaleness or maleness. During puberty, all children need help in maintaining a good self-image.

Adolescence follows puberty and often brings with it conflicts between children and parents or caregivers. This is because, as humans advance into adolescence, physical changes are often matched by new cognitive abilities and a desire to achieve greater independence from the family unit. The desire for independence generally manifests itself in a number of ways. One is that adolescents may want to dress according to their own tastes, sporting unconventional clothes and hairstyles that may annoy or alarm their parents. Another is that adolescents often begin to place great importance on having their own friends and ideas, sometimes purposefully different from what parents desire. The influence of peers in particular seems to threaten parental influence.

Both parents and adolescents may experience the strain of this period in physical and emotional development. Parents, on the one hand, may feel an intense need to protect their adolescent from engaging in behavior for which he or she is not cognitively or emotionally ready (Tharinger, 1987). They may fear that their child will be hurt or that deeply held cultural or religious values will be sacrificed. On the other side of the equation, youth may be primarily concerned with developing an identity separate from their parents and with experiencing their rapidly developing physical, emotional, and cognitive selves (Dacey, 1986).

All of the above statements regarding development apply to most children, regardless of whether they have a disability or not. It is important to understand that all children follow this developmental pattern, some at a slower and perhaps less intense rate, but all eventually grow up.

What is Sexuality Education?

What does it mean to provide sexuality education to children and youth? What type of information is provided and why? What goals do parents, caregivers, and professionals have when they teach children and youth about human sexuality?

Sexuality education should encompass many things. It should not just mean providing information about the basic facts of life, reproduction, and sexual intercourse. "Comprehensive sexuality education addresses the biological, sociocultural, psychological, and spiritual dimensions of sexuality" (Haffner, 1990, p. 28). According to the Sex Information and Education Council of the U.S., comprehensive sexuality education should address:

- facts, data, and information;
- feelings, values, and attitudes; and
- the skills to communicate effectively and to make responsible decisions. (Haffner, 1990, p. 28)

This approach to providing sexuality education clearly addresses the many facets of human sexuality. The goals of comprehensive sexuality education, then, are to:

- ***Provide information.*** All people have the right to accurate information about human growth and development, human reproduction, anatomy, physiology, masturbation, family life, pregnancy, childbirth, parenthood, sexual response, sexual orientation, contraception, abortion, sexual abuse, HIV/AIDS, and other sexually transmitted diseases.
- ***Develop values.*** Sexuality education gives young people the opportunity to question, explore, and assess attitudes, values, and insights about human sexuality. The goals of this exploration are to help young people understand family, religious, and cultural values, develop their own values, increase their self-esteem, develop insights about relationships with members of both genders, and understand their responsibilities to others.
- ***Develop interpersonal skills.*** Sexuality education can help young people develop skills in communication, decision-making, assertiveness, peer refusal skills, and the ability to create satisfying relationships.

➥ ***Develop responsibility.*** Providing sexuality education helps young people to develop their concept of responsibility and to exercise that responsibility in sexual relationships. This is achieved by providing information about and helping young people to consider abstinence, resist pressure to become prematurely involved in sexual intercourse, properly use contraception and take other health measures to prevent sexually-related medical problems (such as teenage pregnancy and sexually transmitted diseases), and to resist sexual exploitation or abuse. (Haffner, 1990, p. 4)

When one considers the list above, it becomes clear that a great deal of information about sexuality, relationships, and the self needs to be communicated to children and youth. In addition to providing this information, parents and professionals need to allow children and youth opportunities for discussion and observation, as well as to practice important skills such as decision-making, assertiveness, and socializing. Thus, sexuality education is not achieved in a series of lectures that take place when children are approaching or experiencing puberty. Sexuality education is a life-long process and should begin as early in a child's life as possible.

Providing comprehensive sexuality education to children and youth with disabilities is particularly important and challenging due to their unique needs. These individuals often have fewer opportunities to acquire information from their peers, have fewer chances to observe, develop, and practice appropriate social and sexual behavior, may have a reading level that limits their access to information, may require special materials that explain sexuality in ways they can understand, and may need more time and repetition in order to understand the concepts presented to them. Yet with opportunities to learn about and discuss the many dimensions of human sexuality, young people with disabilities can gain an understanding of the role that sexuality plays in all our lives, the social aspects to human sexuality, and values and attitudes about sexuality and social and sexual behavior. They also can learn valuable interpersonal skills and develop an awareness of their own responsibility for their bodies and their actions. Ultimately, all that they learn prepares them to assume the responsibilities of adulthood, living, working, and socializing in personally meaningful ways within the community.

The books, journal articles, and videos listed throughout this *NEWS DIGEST* represent only some of the materials available. If you are interested in obtaining a resource listed in this document, first check with your local library. If the library does not have the resource you are seeking, then you may want to contact the publisher.

We have listed the names, addresses, and telephone numbers of the publishers at the end of this document. **Prices for materials will range from no or low cost up to several hundred dollars for some of the video programs listed. Many of these video programs can be rented at lower cost through Planned Parenthood. To help you identify the resources most affordable to you, we have marked most of the resources with an A, B, C, D, E, or F. These letters correspond to the following price ranges (not including any charges for postage and handling):**

A No cost to $10.00	**C** $25.01 to $50.00	**E** $100.01 to $200.00
B $10.01 to $25.00	**D** $50.01 to $100.00	**F** Over $200.00

The prices of materials and the addresses and telephone numbers of publishers are, of course, subject to change without notice.

References

Calderone, M.S., & Johnson, E.W. (1990). *The family book about sexuality* (rev. ed.). New York: Harper Collins. (A)

Dacey, J.S. (1986). *Adolescents today* (3rd ed.). Glenview, IL: Scott, Foresman & Company. (This book has gone out of print but may be available through your public library.)

Edwards, J.P., & Elkins, T.E. (1988). *Just between us: A social sexual training guide for parents and professionals who have concerns for persons with retardation.* Portland: Ednick. (B)

Gardner, N.E.S. (1986). Sexuality. In J.A. Summers (Ed.), *The right to grow up: An introduction to adults with developmental disabilities* (pp. 45-66). Baltimore, MD: Paul H. Brookes. (This book has gone out of print but may be available through your public library.)

Haffner, D.W. (1990, March). *Sex education 2000: A call to action.* New York: Sex Information and Education Council of the U.S. (B)

Hingsburger, D. (1990). *I contact: Sexuality and people with developmental disabilities.* Mountville, PA: Vida. (B)

Sugar, M. (Ed.). (1990). *Atypical adolescence and sexuality.* New York: W.W. Norton. (C)

Tharinger, D.J. (1987). Sexual interest. In A. Thomas & J. Grimes (Eds.), *Children's needs: Psychological perspectives.* Washington, DC: National Association of School Psychologists. (C)

Way, P. (1982). *The need to know: Sexuality and the disabled child.* Eureka, CA: Planned Parenthood of Humboldt County. (A)

Weiner, F. (Ed.) (1986). *No apologies.* New York: St. Martin's Press. (B)

THE IMPORTANCE OF DEVELOPING SOCIAL SKILLS

In order to build gratifying human relationships, it is vital that children with disabilities learn and have the opportunity to practice the social skills considered appropriate by society. This article addresses some of the issues involved in teaching children with disabilities to conduct themselves in ways that allow them to develop relationships with other people. Many will find this more difficult than their peers without disabilities, because of learning or other cognitive disabilities, visual or hearing impairments, or a physical disability that limits their chances to socialize. Most, however, are capable of learning these important "rules" (Duncan & Canty-Lemke, 1986).

Consider how we ourselves learned society's social rules. We, as children, made mistakes. We were corrected by our parents or others; sometimes we were punished. Sometimes friends got mad at things we did or said. And, given this feedback, we gradually learned. Unfortunately, all too often, this important feedback on performance is denied those with disabilities (Duncan & Canty-Lemke, 1986). For some, there is a presumption that they cannot learn the basics of social behavior. For others, social isolation plays a key role; how can there be feedback on one's social skills when little socializing takes place?

Acquiring socialization skills does not happen overnight. These skills are developed across years of observation, discussion, practice, and constructive feedback. Some of the most important aspects of socializing that individuals with disabilities may initially have difficulty grasping include turn-taking during conversations, maintaining eye contact, being polite, maintaining attention, repairing misunderstandings, finding a topic that is of mutual interest, and distinguishing social cues (both verbal and nonverbal). These subtleties, however, are not impossible for individuals with disabilities to learn. According to Edwards and Elkins (1988), "socialization skills are learned every day" (p. 29). This training can begin at home, with you as the parents playing a vital role in helping your child learn how to socialize. Edwards and Elkins suggest, for example, that when entertaining, you should not have your child safely tucked into bed before guests arrive. Instead, make sure your child has a part to play in the festivities. This might be greeting people at the door, taking their coats, showing them where the chairs are, or offering them food. You may find it helpful to take one aspect at a time and practice it with your child in advance (e.g., how and when to shake hands). Even those with severe disabilities can be creatively included. Remember, these early interactions lay the foundation for interactions in the future, many of which will take place outside of the home.

> ***Because we never talked about the feelings people might have about me or about how other people might see me, I didn't develop the skills I needed socially.*** **(Katherine C., in Weiner, 1986, p. 78)**

As most children grow older, they interact more and more with people in situations where direct supervision by parents is not possible. Drawing from what they have learned at home about socializing, children make friends within their peer group and soon learn more about socializing, hopefully refining their social skills as they grow and mature. These friendships are important for all children to develop, not only because contact, understanding, and sharing with others are basic human needs. Friends also "serve central functions for children that parents do not, and they play a crucial role in shaping children's social skills and their sense of identity" (Rubin, 1980, p. 12).

Unfortunately, many children with disabilities are socially isolated. They may have great difficulty building a network of friends and acquaintances with whom to share their feelings, opinions, ideas, and selves. A number of factors may contribute to their becoming isolated. The presence of a disability may make peers shy away, may make transportation to and from social events difficult, may require special health care, or may make the individual with the disability reluctant to venture out socially. A lack of appropriate social skills may also contribute to a person's social isolation.

Families and caregivers can help children and youth with disabilities widen their social circle in a number of ways. As has been said, the first involves laying the foundations of socializing at home, from early childhood on. (This includes emphasizing good grooming and personal hygiene, and teaching children the basics of self-care.) Another way you can help is by discussing and exploring with your child what makes for good friendships, how friendships are formed and maintained, and some reasons why friendships may end. Children and youth with disabilities need to be aware that they may have to be the *initiator* in forming friendships. In the beginning, this may be difficult for young people with disabilities. You may wish to model important social behaviors for your child and then have your child role-play with you or other family members any number of typical friendly interactions. Such interactions might include phone conversations, how to ask about another person's interests or describe one's own interests, how to invite a friend to the house, or how to suggest or share an activity with a friend. Other suggestions you may want to consider are:

➥ *Help your child to develop hobbies or pursue special interests.* Not only are hobbies gratifying in themselves, but shared hobbies or interests bring people together and provide opportunities for friendships to develop.

➥ *Encourage your child to pursue recreational and leisure activities in the community.* These might include Scouts, the 4-H Club, a church group, and activities through the parks and recreation department, local community centers, or the YMCA/YWCA. These provide healthy outlets for youthful energy, build self-esteem through developing competence, and provide occasions for the young person to interact with peers of the same age.

➥ *Encourage your child to participate in extracurricular activities at school.* Most schools have special-interest activities or

clubs that bring together students with similar interests. Even after-school day care programs offer many opportunities for socialization.

➥ *Be alert to opportunities for your child to become involved creatively at school.* One mother of a teenaged boy with multiple disabilities talked with the high school football coach about how her son could contribute managerially to the team's activities. Alex became waterboy for the varsity football team and currently travels to all games with the team. He now knows all the football players, the cheerleaders, and their friends, a major social "coup" at his school.

➥ *Help your teenager find employment or volunteer positions in the community.* Working after school or on the weekends in the community offers opportunities for social interaction and certainly enhances self-esteem.

➥ *Try not to overprotect your child.* Although it is natural to want to shield your child from the possibility of failure, hurt feelings, and others' rejection, you must allow your child the opportunity to grow and stretch socially. Be available to talk about difficulties your child is having socially and about his or her fears, questions, and feelings. When attempts to build a friendship don't work out, encourage your child to try again.

Beyond developing basic interpersonal skills, there are two types of social mistakes that many individuals with disabilities will need special help to avoid. These are: stranger-friend errors and private-public errors (Duncan & Canty-Lemke, 1986, p. 25). A *stranger-friend error* occurs when the person with a disability treats an acquaintance or a total stranger as if he or she were a dear and trusted friend. Individuals with mental retardation are particularly vulnerable to making these kinds of mistakes —for example, hugging or kissing a stranger who comes to the family home. *Private-public errors* generally involve doing or saying something in public that society considers unacceptable in that context, such as touching one's genitals or undressing in plain view of others. Committing either type of error can put the person with a disability into a vulnerable position in terms of breaking the law or opening the door to sexual exploitation.

The majority of individuals with disabilities who are likely to commit stranger-friend errors or private-public errors can learn to avoid them, but it's important to start this type of training when children are quite young (Edwards & Elkins, 1988). One effective means of teaching children with disabilities to avoid making stranger-friend errors is called the *Circles Method of Teaching Social Behavior*. Developed by Leslie Walker-Hirsch and Marklyn P. Champagne and used in workshops and schools around the country, *Circles* is a simple but ingenious way to teach and clarify who is okay to hug regularly or infrequently, who you should shake hands with or greet with a hello, and who you should not speak to (Kempton, 1988).

Most individuals with disabilities can learn fairly early in life how to avoid private-public errors as well. The difference between public and private, however, may be a difficult notion for some individuals with disabilities to grasp, particularly those with moderate or severe mental retardation. It is well recognized that many people with disabilities have virtually no privacy (Griffiths, Quinsey, & Hingsburger, 1989). So it is not surprising that they may not initially understand that society considers a behavior inappropriate in one location (i.e., undressing in a public park) but appropriate in another (i.e., undressing in the privacy of the bathroom).

"You can teach the distinction between public and private most effectively through modelling, explanation, and persistence."

You can teach the distinction between public and private most effectively through modelling, explanation, and persistence. When you teach the skills of personal grooming, for example, do so in a private place. "Close the bathroom or bedroom door and tell your child...that this is a private behavior so we close the door" (Edwards & Elkins, 1988, p. 100). When your child commits public-private errors, such as touching his or her genitals, immediately and calmly say, "No, that's private. We don't touch ourselves in public." If possible, allow the child to go to a private place, but if this is not possible, focus the child's attention on something else and discuss appropriate behavior later at home. It is also important that children and youth be given privacy. Not only does this allow them to understand the difference between public and private, but it acknowledges their right as individuals to have and enjoy time alone. "It is the reinforcement of the concept of public and private behaviors that provides the guidelines for decision making related to social-sexual activity that your child must make throughout his or her life" (Edwards & Elkins, 1988, p. 57).

The "normal" child can get away from watchful adults. From childhood through young manhood, I was on public display while I ate, slept, or defecated, and there was no means for me to have sexual experience. It is humiliating to be called a "nice boy" at the age of twenty-seven.

Responsibility is a concomitant of maturity. In my institution, patients were given no personal responsibilities. All decisions, even the most insignificant, were made for us. These circumstances perpetuate the unhappy phenomenon I call "the elderly adolescent." **(Albert D., in Weiner, 1986, p. 42)**

References

Duncan, D., & Canty-Lemke, J. (1986, May). Learning appropriate social and sexual behavior: The role of society. *Exceptional Parent*, 24-26. (A)

Edwards, J.P., & Elkins, T.E. (1988). *Just between us: A social sexual training guide for parents and professionals who have concerns for persons with retardation.* Portland: Ednick. (B)

Griffiths, D.M., Quinsey, V.L., & Hingsburger, D. (1989). *Changing inappropriate sexual behavior.* Baltimore: Paul H. Brookes. (B)

Kempton, W. (1988). *Sex education for persons with disabilities that hinder learning: A teacher's guide.* Santa Barbara, CA: James Stanfield. (B)

Rubin, Z. (1980). *Children's friendships.* Cambridge, MA: Harvard University Press. (A)

Weiner, F. (Ed.) (1986). *No apologies.* New York: St. Martin's Press. (B)

Resources

Camp, B.W., & Bash, M.A. (1981). *Think aloud: Increasing social and cognitive skills - A problem-solving program for children, primary level.* Champaign, IL: Research Press. (C)

Cartledge, G., & Milburn, J.F. (Eds.). (1986). *Teaching social skills to children: Innovative approaches* (2nd ed.). Elmsford, NY: Pergamon Press. (B)

Champagne, M., & Walker-Hirsch, L. (1982, Fall). Circles: a self-organization system for teaching appropriate social/sexual behavior to mentally retarded/developmentally disabled persons. *Sexuality and Disability, 5*(3), 172-7. (A)

Champagne, M., & Walker-Hirsch, L. (1988). *Circles I: Intimacy and relationships.* Santa Barbara, CA: James Stanfield. (F)

Goldstein, A.P. (1988). *The PREPARE curriculum: Teaching prosocial competencies.* Champaign, IL: Research Press. (C)

Goldstein, A.P., Sprafkin, R.P., Gershaw, N.J., & Klein, P. (1980). *Skillstreaming the adolescent: A structured learning approach to teaching prosocial skills.* Champaign, IL: Research Press. (B)

Interstate Research Associates. (1989, October). *Teaching social skills to elementary school-age children: A parent's guide.* McLean, VA: Author. (B)

Interstate Research Associates. (1989, December). *Improving social skills: A guide for teenagers, young adults, and parents.* McLean, VA: Author. (B)

> ***People with disabilities, like myself, were trained to accept that they have to be "nice kids" and know all the rules. Many people do not like it if you speak up. They feel it is enough that people tolerate you; you shouldn't put any extra pressure on them. This can keep you in a very passive position, a hard mold to break out of. Assertion is a natural outgrowth of feeling good, feeling worthwhile, thinking, "Why shouldn't what I want be valid?"***
> **(Harilyn R., in Weiner, 1986, p. 9)**

Jackson, N.E., Jackson, D.A., & Monroe, C. (1983). *Getting along with others: Teaching social effectiveness to children.* Champaign, IL: Research Press. (C)

Lehr, S., & Taylor, S.J. (1987). *Teaching social skills to youngsters with disabilities: A manual for parents.* Boston, MA: Federation for Children with Special Needs and the Center on Human Policy. (A)

Lutfiyya, Z.M. (1991, April). *Personal relationships and social networks: Facilitating the participation of individuals with disabilities in community life.* Syracuse, NY: The Center on Human Policy. (A)

Matson, J.L., & Ollendick, T.H. (1988). *Enhancing children's social skills: Assessment and training.* Elmsford, NY: Pergamon Press. (B)

McGinnis, E., Goldstein, A.P., Sprafkin, R.P., & Gershaw, N.J. (1984). *Skillstreaming the elementary school child: A guide for teaching prosocial skills.* Champaign, IL: Research Press. (B)

Mind your manners. (1991). Santa Barbara, CA: James Stanfield. (This 6-part video program introduces students to proper social behavior necessary for success in everyday situations. The program includes an introduction to why manners are important and explores manners at home, table manners, manners at school, manners in public, and greetings and conversations.) (F)

Searcy, S. (1988). *Teaching social skills to young children: A parent's guide.* McLean, VA: Interstate Research Associates. (B)

Socialization and sex education: The Life Horizons curriculum module. (1991). Santa Barbara, CA: James Stanfield. (This set of teaching instructions is designed for professionals who want to help their students understand themselves better socially, physically, and psychologically.) (F)

TIPS. (1991). Santa Barbara, CA: James Stanfield. (This 7-part program gives students 150 "tips" for successful social interaction. The different parts are: Getting along with others, getting to know others, getting along with adults, having friends, enjoying free time, living in the community, and being on the job. The program is available in slide or video formats.) (F)

Valenti-Hein, D., & Mueser, K.T. (1991). *The dating skills program: Teaching social-sexual skills to adults with mental retardation.* Worthington, OH: International Diagnostic Services, Inc. (C)

Walker, H.M., McConnell, S., Holmes, D., Todis, B., Walker, J., & Golden, N. (1983). *Walker social skills curriculum: The ACCEPTS program.* Austin, TX: Pro-Ed. (C for curriculum guide; F for video)

TEACHING CHILDREN AND YOUTH ABOUT SEXUALITY

The vast majority of parents want to be — and, indeed, already are — the primary sex educators of their children (Sex Information and Education Council of the U.S., 1991). Parents communicate their feelings and beliefs about sexuality continuously. Parents send messages to their child about sexuality both verbally and nonverbally, through praise and punishment, in the interactions they have with their child, in the tasks they give the child to do, and in the expectations they hold for the child. Children absorb what parents say and do not say, and what they do and do not do, and children learn.

Of course, a great deal of education about socialization and sexuality takes place in settings outside the home. The school setting is probably the most important, not only because most students take classes in sexuality education, but also because it is there that children and youth encounter the most extensive opportunities to socialize and mix with their peers. Thus, both parents and the school system assume responsibility for teaching children and youth about appropriate behavior, social skills, and the development of sexuality. Parents are strongly encouraged to get information about what sexuality education is provided by the school system and to work together with the school system to ensure that the sexuality education their child receives is as comprehensive as possible.

This section offers some practical suggestions for how to take an active role in teaching children with a disability about sexuality. Although it is written primarily to parents, the information and list of resources should be helpful to professionals as well. The discussion below is organized by age groupings and the specific types of sexuality training that can be provided to children as they grow and mature. Although physical development is not much delayed for most individuals with disabilities, a child may not show certain behaviors or growth at the times indicated below. Depending on the nature of the disability, emotional maturity may not develop in some adolescents at the same rate as physical maturity. This does not mean that physical development won't occur. It will. Parents can help their child to cope with physical and emotional development by anticipating it and talking openly about sexuality and the values and choices surrounding sexual expression. This will help prepare children and youth with disabilities to deal with their feelings in a healthy and responsible manner. It's important to realize that discussing sexuality will not *create* sexual feelings in young people. Those feelings are already there, because sexuality is a part of each human being throughout the entire life cycle.

> ***Learning about oneself and sexuality is an emotional and psychological journey.***
> **(Hingsburger, 1990, p. 189)**

> ***"It's important to realize that discussing sexuality will not <u>create</u> sexual feelings in young people. Those feelings are already there, because sexuality is a part of each human being throughout the entire life cycle."***

Infancy through 3 years old. Infants and young children find great pleasure in bodily sensations and exploration. Fascination with genitals is quite normal during this period and should not be discouraged or punished by parents or caregivers. Similarly, "accidents" during toilet training should not be punished or shamed, for that is all they are — accidents, in the process of learning. When a young child holds or fondles his or her own genitals, parents need not react with harshness, for the child is merely curious and the sensation may very well be a pleasant one. (Of course, it may also be that the child merely has to go to the bathroom or that his or her pants are uncomfortable!) When a child of three holds his or her genitals in public, you may wish to move the child's hand and say quietly but firmly, "We don't do that in public." Then offer diversion — "look at that!" or play a game such as peek-a-boo or "chase" — to change the child's focus. Most children of three or four are capable of understanding the basic difference between "public" and "private." You can put the concepts in terms they are likely to understand, such as "being with others" or "being alone." Children with cognitive impairments may not be able to understand the public/private concept as yet. For these children, parents can begin making concrete distinctions between public and private situations, for this is how the children will eventually learn the difference.

Preschool (Ages 3 through 5). Parents are usually teaching their children the names of body parts during this period, although the process may start earlier for some children and later for others, depending on the nature of the child's disability and his or her facility for language acquisition. When you are teaching the names of body parts, it is important not to omit naming the sexual organs. Take advantage of the natural learning process to teach your child what the sexual organs are called. It's a good idea to be accurate about the names, too, just as you are when you teach your child the names for eyes, nose, arms, and legs. Boys have a penis, for example, not a "pee-pee." Being accurate and matter-of-fact now saves having to re-teach correct terminology later, and avoids communicating that the sexual organs are somehow taboo or must be referred to in secretive, nonspecific ways. Remember that children do not interpret the world from the same perspective as adults. They will not spontaneously invest the sexual organs with values or hidden meanings; these are reactions they learn from others.

During this period, most children also become intensely curious not only about their own bodies but those of others. While exploration and "show me" games may be unsettling to you, remember that healthy

We were brought up to feel – and be — dependent, to want to be dependent. Mom wanted to take care of us. Dad wanted to take care of us. And then you read about feminism, where you are independent, you can do what you want. First of all, you have to incorporate that into yourself and believe in yourself. When you finally believe that you are an independent, liberated woman, the rest of the world still treats you like you are a disabled, dependent woman, and it drives you nuts! (Susan L.T., in Weiner, 1986, p. 68)

curiosity prompts these games. The messages you send in your reaction, and how strong and emotional your reaction is, teach your child a great deal about the acceptability of the body and curiosity itself. It's important not to overreact. Calm remarks such as "Please put your clothes back on and come inside" give a more positive message than "Shame on you! Come in here *this minute!*" Soon afterwards, make sure you talk to your child in simple, basic terms about his or her body and appropriate behavior. Detailed discussions of anatomy or reproduction are not necessary and, when offered to a young child, are generally met with boredom (Kempton, 1988).

A great concern of parents and professionals is that children with disabilities are more vulnerable to sexual exploitation. Therefore, one message that *is* important to start mentioning when children are young is that their body belongs to *them*. There are many good reasons for some adults to look at or touch children's bodies (such as a parent giving a child a bath), but beyond that, children have the right to tell others not to touch their body when they do not want to be touched. Likewise, your child should hear from you that he or she should not touch strangers. Children of this age should also be taught that if a stranger tries to persuade them to go with him or her, they should leave at once and tell a parent, neighbor, or other adult (National Guidelines Task Force, 1991). For more information about the issue of sexual exploitation and abuse, refer to the SPECIAL ISSUES article in this *NEWS DIGEST* (page 22).

Ages 5 through 8. These are the early school years, when many children tend to lose interest in the opposite sex but may still continue to explore the body with same sexed friends. While this may concern some parents, again, they should try to control the severity of their reaction, for such exploration is an expression of curiosity and is natural and normal. The child's need for information about all kinds of topics — not just the body — increases. Socialization skills are important to emphasize and practice during this period. Children with disabilities can also benefit from activities that bolster self-esteem as they grow and develop. For example, children with disabilities should have household responsibilities that they are capable of performing or learning to perform, given their disability, for accomplishment and a sense of competency build self-esteem.

It's important during this age period to become more specific in teaching about sexuality. Up to this point, training has focused more on the social self, avoiding negative messages about the body and its exploration, and communicating positive messages ("your body is good, it's yours, your feelings about yourself and your body are good"). According to the National Guidelines Task Force (1991), some topics that may need to be addressed during this age group are:

- the correct names for the body parts and their functions;
- the similarities and differences between girls and boys;
- the elementals of reproduction and pregnancy;
- the qualities of good relationships (friendship, love, communication, respect);
- decision-making skills, and the fact that all decisions have consequences;
- the beginnings of social responsibility, values, and morals;
- masturbation can be pleasurable but should be done in private; and
- avoiding and reporting sexual exploitation.

Here are several suggestions you may wish to consider when approaching discussions of sexuality with your child:

- Not all discussions need to be lectures or situations where you sit your child down "to talk about sex." There are many daily "teachable moments" that you can take advantage of to initiate a relaxed discussion. Such moments can range from a situation on a television show, a pregnancy of a friend or relative, diapering a baby, or a question about sex that a child or youth suddenly asks.
- Bring home books about sexuality from the public library and share them with your child, much as you would any other type of book. Curl up together and read, look at the illustrations, and talk about the content in a relaxed manner.
- When you wish your child to learn a particular value or behavior about sexuality, make sure you give your reasons for that value or behavior. This enables the child to understand why the value or behavior is important.
- You can help your child become aware of the appropriateness of the different word systems that can be used when talking about sexuality. Share your feelings about different terms and give your child the language you prefer. For example, you can say, "The correct word is..." or "I prefer..." and give a reason why.
- Tailor information to the needs of your child. For children with mental retardation, for example, a small amount of information should be given at a time, in simple, concrete terms, perhaps supported by illustrations. (See the next article in this *NEWS DIGEST* for how to adapt your teaching to the needs of your child.)

Ages 8 through 11. Pre-teens are usually busy with social development. They are becoming more preoccupied with what their peers think of them and, for many, body image may become an issue. If we think of the emphasis placed on physical beauty within our society — "perfect bodies," exercise, sports, make-up — it is not difficult to imagine why many pre-teens with disabilities (and certainly teenagers) have trouble feeling good about their bodies. Those with disabilities affecting the body may be particularly vulnerable to low self-esteem in this area.

There are a number of things parents and professionals can do to help children and youth with disabilities improve self-esteem in regards to body image. The first action parents and professionals can take is to listen to the child and allow the freedom and space for feelings of sensitivity, inadequacy, or unhappiness to be expressed. Be careful not to wave aside your child's concerns, particularly as they relate to his or her disability. If the disability is one that can cause your child to have legitimate difficulties with body image, then you need to acknowledge that fact calmly and tactfully. The disability is there; you know it and your child knows it. Pretending otherwise will not help your child develop a balanced and realistic sense of self.

What *can* help is encouraging children with disabilities to focus on and develop their strengths, not what they perceive as bad points about their physical appearance. This is called "refocusing" (Pope, McHale, & Craighead, 1988). Many parents have also helped their child with a disability improve negative body image by encouraging improvements that can be made through good grooming, diet, and exercise. While it's important not to teach conformity for its own sake, fashionable clothes can often help any child feel more confident about body image.

One of the most important things that parents can do during their children's prepubescent years is to prepare them for the changes that their bodies will soon undergo. No female should have to experience her first menses without knowing what it is; similarly, boys should be told that noctural emissions (or "wet dreams," as they are sometimes known) are a normal part of their physical development. To have these experiences without any prior knowledge of them can be very upsetting to a young person, a trauma that can easily be avoided by timely discussions between parent and child. Tell your child that these experiences are a natural part of growing up. Above all, do so *before* they occur. Warning signs of puberty include a rapid growth spurt, developing breast buds in girls, and sometimes an increase in "acting out" and other emotional behaviors.

In addition to the topics mentioned above, other topics of importance for parents to address with children approaching puberty are:

- Sexuality as part of the total self;
- More information on reproduction and pregnancy;
- The importance of values in decision-making;
- Communication within the family unit about sexuality;
- Masturbation (see discussion below);
- Abstinence from sexual intercourse;
- Avoiding and reporting sexual abuse; and
- Sexually transmitted diseases, including HIV/AIDS.

Puberty and adolescence are usually marked by feelings of extreme sensitivity about the body. Your child's concerns over body image may become more extreme during this time. Let your adolescent voice these concerns, and reinforce ideas you've introduced about refocusing, good grooming, diet, and exercise. Without dismissing the feelings as a "phase you are going through," try to help your child understand that some of the feelings are a part of growing up. Parents may arrange for the youth to talk with the family doctor without the parent being present. If necessary, parents can also talk to the doctor in advance to be sure he or she will be clear about the adolescent's concerns. If, however, your child remains deeply troubled or angry about body image after supportive discussion within the family unit, it may be helpful to have your child speak with a professional counselor. Counseling can be a good outlet for intense feelings, and often counselors can make recommendations that are useful to young people in their journey towards adulthood.

> *When I was younger...I remember wearing my hair pulled back and having my hearing aids exposed. Everyone saw them. When I got to be an adolescent, I became very self-conscious about the way I looked. I wore my hair covering my hearing aids. Even now, I won't wear my hair back.* (Nina M., in Weiner, 1986, p. 71)

Adolescence (12 years to 18 years). During this period it is important to let your child assume greater responsibility in terms of decision-making. It is also important that adolescents have privacy and, as they demonstrate trustworthiness, increasingly greater degrees of independence. For many teenagers, this is an active social time with many school functions and outings with friends. Many teenagers are dating; statistics show that many become sexually involved. For youth with disabilities, there may be some restrictions in opportunities for socializing and in their degree of independence. For some, it may be necessary to continue to teach distinctions between public and private. Appropriate sexuality means taking responsibility and knowing that sexual matters have their time and place.

One topic that many parents find embarrassing to talk about with their children is masturbation. You will probably notice an increase in self-pleasuring behavior at this point in your child's development (and oftentimes before) and may feel in conflict about what to do, because of personal beliefs you hold. However, beliefs about the acceptability of this behavior are changing. The medical community, as well as many religious groups, now recognize masturbation as normal and harmless. Masturbation "can be a way of becoming more comfortable with and/or enjoying one's sexuality by getting to know and like one's body" (Sex Information and Education Council of the U.S., 1991, p. 3). Masturbation only becomes a problem when it is practiced in an inappropriate place or is accompanied

I realized that...parents (may not see their child's) other important, albeit less tangible needs – to grow and develop, to become independent, and to learn to be on one's own, even if under some supervision; and most important, like every other young person, to eventually make the transition of separating from the parents... **(Betty P., in Weiner, 1986, p. 39)**

by strong feelings of guilt or fear (Edwards & Elkins, 1988).

How can you avoid teaching your child guilt over a normal behavior, if you yourself are not convinced? First, you may wish to talk to your family doctor, school nurse, or clergy. You may be surprised to find that what you were taught as a child is no longer being approached in the same way. Read the books and articles listed in the resource section at the end of this article; they offer many ideas and suggestions about this behavior. In dealing with your child, recognize that you communicate a great deal through your actions and reactions, and have the power to teach your child guilt and fear, or that there are appropriate and inappropriate places for such behavior.

Teach your child that touching one's genitals in public is socially inappropriate and that such behavior is only acceptable when one is alone and in a private place. Starting from very early in your child's life when you may first notice such behavior, it is important to accept the behavior calmly. When young children touch themselves in public, it is usually possible to distract them. During adolescence (and sometimes before), masturbation generally becomes more than an infrequent behavior of childhood, and distracting the youth's attention will not work. Furthermore, it denies the real needs of the person, instead of helping him or her to meet those needs in acceptable ways (Edwards & Elkins, 1988).

There are many other topics that your adolescent will need to know about. Among these are:

- Health care, including health-promoting behaviors such as regular check-ups, and breast and testicular self-exam;
- Sexuality as part of the total self;
- Communication, dating, love, and intimacy;
- The importance of values in guiding one's behavior;
- How alcohol and drug use influence decision-making;
- Sexual intercourse and other ways to express sexuality;
- Birth control and the responsibilities of child-bearing;
- Reproduction and pregnancy (more detailed information than what has previously been presented); and
- Condoms and disease prevention.

Many resources are available about each one of these areas to help you plan what information to communicate and how this might best be communicated. Don't forget that your family physician and school health personnel can be good sources of accurate information and guidance. Depending on the nature of your child's disability, you may have to present information in very simple, concrete ways, or discuss the topics in conjunction with other issues. Your responses will convey your beliefs and reflect your standards of behavior. Remember, young people are receiving information from other sources as well. It may be essential to include the entire family in your resolve to be frank and forthright, for a lot of information comes from siblings. Children may feel more comfortable asking their brothers and sisters questions than directly asking you.

Because sexuality involves so much more than just having sexual intercourse, parents will also need to devote time to talking with their child about the values that surround sexuality: intimacy, self-esteem, caring, and respect. Encourage your child to be involved in activities with others that provide social outlets, such as going to the community recreation center on weekends, going to sports events or a movie, joining a club or group at school or in the community, or having a friend over after school. These interactions help build social skills, develop a social network for your child, and provide him or her with opportunities to channel sexual energies in healthy, socially acceptable directions (Murphy & Corte, 1986).

References

Edwards, J.P., & Elkins, T.E. (1988). *Just between us: A social sexual training guide for parents and professionals who have concerns for persons with retardation.* Portland, OR: Ednick. (B)

Hingsburger, D. (1990). *I contact: Sexuality and people with developmental disabilities.* Mountville, PA: Vida. (B)

Kempton, W. (1988). *Sex education for persons with disabilities that hinder learning: A teacher's guide.* Santa Barbara, CA: James Stanfield. (B)

Murphy, L., & Corte, S.D. (1986). Sex education for the special person. *Special Parent/ Special Child, 2*(2), 1-5.

National Guidelines Task Force. (1991). *Guidelines for comprehensive sexuality education: Kindergarten - 12th grade.* New York: Sex Information and Education Council of the U.S. (A)

Pope, A.W., McHale, S.M., & Craighead, W.E. (1988). *Self-esteem enhancement with children and adolescents.* New York: Pergamon. (B)

Sex Information and Education Council of the U.S. (1991). *SIECUS position statements 1991.* New York: Author. (A)

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Resources

American Academy of Pediatrics, Committee on Adolescence. (1988). *Sex education: A bibliography of educational materials for children, adolescents, and their families.* Elk Grove Village, IL: Author. (A)

Azarnoff, P. (1983). *Health, illness, and disability: A guide to books for children and young adults.* New York: R.R. Bowker. (C)

Callanan, C.R. (1990). Sexuality and sex education. In *Since Owen: A parent-to-parent guide for care of the disabled child* (pp. 375-386). Baltimore, MD: Johns Hopkins University Press. (B)

Center for Early Adolescence, University of North Carolina at Chapel Hill. (1989). *Early adolescent sexuality: Resources for professionals, parents and young adolescents.* Carrboro, NC: Author. (A)

Center for Population Options. (1989, September). *Adolescents, AIDS, and HIV: Resources for educators.* Washington, DC: Author. (A)

Fitz-Gerald, M., & Fitz-Gerald, D.R. (1987). Parents' involvement in the sex education of their children. *Volta Review, 89*(5), 96-110. (A)

Gardner-Loulan, J., Lopez, B., & Quackenbush, M. (1991). *Period* (rev. ed.). San Francisco: Volcano. (A)

Gordon, S., & Gordon, J. (1989). *Raising a child conservatively in a sexually permissive world* (rev. ed.). New York: Simon & Schuster. (A)

Ikeler, B. (1990, July). Teaching about sexuality. *Exceptional Parent, 20*(5), 24-26. (A)

Johnson, E.W. (1985). *People, love, sex, and families: Answers to questions preteens ask.* New York: Walker. (B)

Johnson, E.W. (1988). *Love and sex in plain language.* New York: Bantam. (This book is written for people in their early teens.) (A)

Johnson, E.W. (1989). *Love, sex, and growing up.* New York: Bantam. (This book is written for pre-teens.) (A)

Klein, E., & Kroll, K. (1992). *Enabling romance: A guide to love, sex, and relationships for disabled people (and the people who care about them).* New York: Crown. (B)

McKown, J.M. (1984-86). Disabled teenagers: Sexual identification and sexuality counseling. *Sexuality and Disability, 7*(1/2), 17-27. (A)

Quackenbush, M., Nelson, M., & Clark, K. (1988). *The AIDS challenge: Prevention education for young people.* Santa Cruz, CA: Network/ETR Associates. (B)

People Building Institute. (1991). *Human sexuality for the disabled: A manual designed to assist human service professionals.* Sheldon, IA: Author. (B)

Planned Parenthood of Alameda/San Francisco. (1984). *Table manners: A guide to the pelvic examination for disabled women and health care providers.* San Francisco: Author. (A)

Popkin, M. H. (1989). *Active parenting for teens: A video-based program.* Marietta, GA: Active Parenting, Inc. (F)

Sandowski, C.L. (1989). *Sexual concerns when illness or disability strikes.* Springfield, IL: Charles C. Thomas. (D)

Sex Information and Education Council of the U.S. (1983). *Oh no! What do I do now? Messages about sexuality: How to give yours to your child.* New York: Author. (A)

Sex Information and Education Council of the U.S. (1990). *Bibliography of religious publications on sex education and sexuality.* New York: Author. (A)

Sex Information and Education Council of the U.S. (1990). *Healthy adolescent sexual development.* New York: Author. (B)

Sex Information and Education Council of the U.S. (1990). *Human sexuality: A bibliography for everybody.* New York: Author. (A)

Siegel, P.C. (1991). *Changes in you for boys.* Richmond, VA: Family Life Education Associates. (A)

Siegel, P.C. (1991). *Changes in you for girls.* Richmond, VA: Family Life Education Associates. (A)

Sobsey, R. (1991). *Disability, sexuality, and abuse: Annotated bibliography.* Baltimore, MD: Paul H. Brookes. (B)

Speaking of sex: Sexuality and the person with special needs. (1988). Santa Barbara, CA: James Stanfield. (D)

Varnet, T. (1984). Sex education and the disabled: Teaching adult responsibilities. *Exceptional Parent, 14*(4), 43-46. (A)

What everyone should know about sexuality and people with disabilities. South Deerfield, MA: Channing L. Bete. (A)

Who wouldn't want me? (1986). In F. Weiner (Ed.), *No apologies* (pp. 54-84). New York: St. Martin's Press. (B)

Understanding that people with disabilities are people with the capacity to love and to care for others is a radical first step. Once accepted, several others follow immediately after – the ability to love forces a view of the handicapped person as an emotional equal. An emotional equal is a political equal, so that if people with disabilities can feel to the same depth as you and I can, then we need to look at our programs and approaches in new ways. **(Hingsburger, 1990, p. 18)**

HOW PARTICULAR DISABILITIES AFFECT SEXUALITY AND SEXUALITY EDUCATION

As has been said, the development of sexuality takes place in all youngsters. Consequently, whether your child has a sensory, orthopedic, mental, emotional, or learning disability, he or she has a genuine need for accurate information about sexuality, as well as the need to accept sexuality as a part of his or her identity.

The type of disability that a child has, however, may affect the way in which information should be presented. The disability may also affect what *type* of information is presented. For example, a person with mental retardation may need information presented in small amounts and in simple, concrete, and basic terms. This person may also need the family and caregivers to stress the distinctions between public and private behavior, as well as how to identify who is a stranger and who is a friend. On the other hand, a young person with a visual impairment would be capable of understanding a wide range of concepts and facts about sexuality but may need materials presenting this information through touch or hearing, or through braille or large print materials. A young person with a physical disability would be similarly capable of understanding material about sexuality, but would not need the information to be presented in alternate formats (e.g., braille or cassette). He or she might, however, need specific information about how the physical disability affects *expression* of sexuality and participation in a sexual relationship. Young people with learning disabilities generally do not require specialized materials or formats to learn about sexuality. They may only need some modification to the pace and manner in which information is presented and increased emphasis on social skills.

> ***I want information and help, not sympathy...I am a loving human being, and it is a strong dream, a strong wish of mine to be with a woman. My ability to love hasn't changed...It is within me...Am I a man? Deep down inside me, I am the same, but on the surface, I am not. But still, I am a man.*** (David, in Weiner, 1986, p. 64)

Thus, tailoring the pace and presentation of information to the needs of each young person is very important. To do so effectively, parents and professionals will need to take into consideration:

- how the child's particular disability may affect his or her social-sexual development;
- how the disability affects the child's ability to learn information about sexual issues; and
- what extra information may need to be provided to address any specific characteristics of a particular disability.

Understanding how a particular disability (e.g., Down Syndrome, deafness, etc.) affects social-sexual development, how it affects the learning process, and how it affects sexual expression can help parents and professionals more effectively approach talking to and teaching children about sexuality.

Fortunately, there is a variety of information available in regards to sexuality education for individuals with particular disabilities. Space limitations in this ***NEWS DIGEST*** prevent us from discussing these issues in the detail that parents and professionals —and, indeed, the individual with a disability — need in order to adequately prepare youth for adult life and responsibilities. Therefore, this section lists resources that can help parents and professionals become informed themselves. This information can be of invaluable help in planning and delivering sexuality education that meets the specific concerns of individuals with particular disabilities. This list is organized by type of disability.

Resources

MENTAL RETARDATION, DEVELOPMENTAL DISABILITIES

Amary, I.B. (1980). *Social awareness, hygiene, and sex education for the mentally retarded.* Springfield, IL: Charles C. Thomas. (B)

Bernstein, N.R. (1990). Sexuality in adolescent retardates. In M. Sugar (Ed.), *Atypical adolescence and sexuality* (pp. 44-56). New York: W.W. Norton. (C)

Caster, J.A. (1988). Sex education. In G.A. Robertson et al. (Eds.), *Best practices in mental disabilities* (Chapter 17). Des Moines, IA: Division of Special Education, Iowa State Department of Public Instruction. (ERIC Document Reproduction Service No. ED 304 845).

Hingsburger, D. (1990). *I contact: Sexuality and people with developmental disabilities.* Mountville, PA: Vida. (B)

Kempton, W., Gordon, S., & Bass, M. (1986). *Love, sex, and birth control for the mentally retarded - A guide for parents.* Philadelphia: Planned Parenthood Association of Southeastern Pennsylvania. (A)

Lieberman, J., & Pascale, B. (producers). (1991). *Person to person.* Silver Spring, MD: American Film & Video. (E)

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LifeFacts 1 and LifeFacts 2. (1990). Santa Barbara, CA: James Stanfield. (F)

Lindemann, J. (1990). *SAFE: An HIV/AIDS curriculum for individuals with MR/DD*. Portland, OR: Oregon Health Sciences University. (D)

McCarthy, W., & Fegan, L. (1984). *Sex education and the intellectually handicapped: A guide for parents and care givers*. Sydney, Australia: ADIS Press. (A)

McClennen, S. (1988, Summer). Sexuality and students with mental retardation. *Teaching Exceptional Children, 20*(4), 59-61. (A)

McClennan, S.E., Hoekstra, R.R., & Bryan, J.E. (1980). *Social skills for severely retarded adults: An inventory and training program*. Champaign, IL: Research Press. (C)

McKee, L., & Blacklidge, V. (1981). *An easy guide for caring parents: Sexuality and socialization: A book for parents of people with mental handicaps*. Walnut Creek, CA: Planned Parenthood of Shasta/Diablo. (A)

Monat-Haller, R.K. (1992). *Understanding and expressing sexuality: Responsible choices for individuals with developmental disabilities*. Baltimore, MD: Paul H. Brookes. (B)

Murphy, D.W., Coleman, E.M., & Abel, G.G. (1983). Human sexuality in the mentally retarded. In J.L. Matson & F. Andrasik (Eds.), *Treatment issues and innovations in mental retardation* (pp. 581-643). New York: Plenum. (D)

Planned Parenthood of Minnesota. (1983). *Learning to talk about sex when you'd rather not*. St. Paul, MN: Author. (This is a 16mm film.) (A, to rent)

Planned Parenthood of Minnesota. (in press). *A guide for teaching human sexuality to the mentally handicapped*. St. Paul, MN: Author. (A)

Planned Parenthood of Minnesota. (1985). *On being sexual*. St. Paul, MN: Author. (This is a 16mm film.) (A, to rent)

Pueschel, S.M. (1988). *The young person with Down Syndrome: Transition from adolescence to adulthood*. Baltimore, MD: Paul H. Brookes. (B)

Pueschel, S.M. (Ed.). (1990). *Parent's guide to Down Syndrome: Toward a brighter future*. Baltimore, MD: Paul H. Brookes. (B)

Rowe, W.S., & Savage, S. (1987). *Sexuality and the developmentally handicapped: A guidebook for health care professionals*. Lewiston, NY: Edwin Mellen Press. (D)

Schwab, W. (1991). *Sexuality in Down Syndrome*. New York: National Down Syndrome Society. (A)

Sex education for persons with disabilities that hinder learning: Speaking of sex. (1988). Santa Barbara, CA: James Stanfield. (B)

Sex Information and Education Council of the U.S. (1991). *Sexuality and the developmentally disabled: An annotated SIECUS bibliography of resources*. New York: Author. (A)

Sexuality education for persons with severe developmental disabilities. (1988). Santa Barbara, CA: James Stanfield. (Program includes 500 slides and teacher's guide.) (F)

Sparks, S., & Caster, J.A. (1989). Human sexuality and sex education. In G.A. Robinson, J.R. Patton, E.A. Polloway, & L.R. Sargent (Eds.), *Best practices in mild mental disabilities* (pp. 289-313). Reston, VA: Council for Exceptional Children, Division on Mental Retardation. (B)

Valenti-Hein, D., & Mueser, K.T. (1991). *The dating skills program: Teaching social-sexual skills to adults with mental retardation*. Worthington, OH: International Diagnostic Services, Inc. (C)

Young Adult Institute (producer). (1986). *Sexuality*. New York: Young Adult Institute. (C, to rent; D, to buy)

Zitzow, D. (1983). *Human sexuality for the mentally retarded*. Ridfield, SD: South Dakota State Division of Elementary and Secondary Education, Pierre. (ERIC Document Reproduction Service No. ED 232 350).

CEREBRAL PALSY

Kroll, K., & Klein, E. (1992). *Enabling romance: A guide to love, sex, and relationships for disabled people (and the people who care about them)*. New York: Crown. (B)

Schleichkorn, J. (1983). *Coping with cerebral palsy: Answers to questions parents often ask*. Austin, TX: Pro-Ed. (B)

United Cerebral Palsy Associations, Inc. (1980). *Strengthening individual and family life*. Lancaster, PA: Author. (A)

United Cerebral Palsy Associations, Inc.. (1983). *Programming for adolescents with cerebral palsy and related disabilities*. Lancaster, PA: Author. (A)

LEARNING DISABILITIES

Cohen, L. (1986, June). Learning disabilities and psychological development. *Churchill Forum, XIII*(4), 1-5. (A)

Haight, S.L., & Fachting, D.D. (1986, June). Materials for teaching sexuality, love and maturity to high school students with learning disabilities. *Journal of Learning Disabilities, 19*(6), 344-350. (A)

Hazel, J.S., Schumaker, J.B., Sherman, J., & Sheldon-Wildgen, J. (1981). *ASSET social school curriculum*. Champaign, IL: Research Press. (F)

Vaughn, S.R., & LaGreca, A.M. (1988). Social interventions for learning disabilities. In Kenneth A. Kavale (Ed.), *Learning disabilities: State of the art and practice* (pp. 123-140). Boston: College-Hill. (C)

Wood, M.H. (1985). Learning disabilities and human sexuality. *Academic Therapy, 20*(5), 543-547. (A)

PHYSICAL DISABILITIES

Barrett, M. (1984). Resources on sexuality and physical disability. *Rehabilitation Digest, 15*(1), 15-18.

Blum, R.W. (1984). Sexual health needs of physically and intellectually impaired adolescents. In R.W. Blum (Ed.), *Chronic illness and disabilities in childhood and adolescence* (pp. 127-141). New York: Grune and Stratton. (D)

Hopper, C.E., & Allen, W.A. (1980). *Sex education for physically handicapped youth.* Springfield, IL: Charles C. Thomas. (B)

Kroll, K., & Klein, E. (1992). *Enabling romance: A guide to love, sex, and relationships for disabled people (and the people who care about them).* New York: Crown. (B)

Neistadt, M.E., & Freda, M. (1987). *Choices: A guide to sex counseling with physically disabled adults.* Malabar, FL: Robert E. Krieger. (B)

Shaman, E. (1985). *Choices: A sexual assault prevention workbook for persons with physical disabilities.* Seattle: Seattle Rape Relief Crisis Center. (A)

VISUAL IMPAIRMENTS

Evans, J.W., & Evans, M.L. (1990). Sensory disability and adolescent sexuality. In M. Sugar (Ed.), *Atypical adolescence and sexuality* (pp. 57-86). New York: W.W. Norton. (C)

Kent, D. (1983). Finding a way through the rough years: How blind girls survive adolescence. *Journal of Visual Impairment and Blindness, 77*(6), 247-250. (A)

Kroll, K., & Klein, E. (1992). *Enabling romance: A guide to love, sex, and relationships for disabled people (and the people who care about them).* New York: Crown. (B)

Neff, J. (1983, June). Sexual well-being: A goal for young blind women. *Journal of Visual Impairment and Blindness, 77*(6), 296-7. (A)

Schuster, C.S. (1986). Sex education of the visually impaired child: The role of parents. *Journal of Visual Impairment and Blindness, 80*(4), 675-680. (A)

Shaman, E. (1985). *Choices: A sexual assault prevention workbook for persons with visual impairments.* Seattle: Seattle Rape Relief Crisis Center. (A)

Wagner, S. (1986). *How do you kiss a blind girl?* Springfield, IL: Charles C. Thomas. (B)

Willoughby, D.M., & Duffy, S. (1989). *Handbook for itinerant and resource teachers of blind and visually impaired students.* Baltimore, MD: National Federation of the Blind. (B)

HEARING IMPAIRMENTS

Bednarczy, A. (1989). *Growing up sexually* (2nd ed.). Washington, DC: Gallaudet, Pre-College Programs. (B for the teacher's guide; B for the student materials)

Fitz-Gerald, M. (1986). *Information on sexuality for young people and their families.* Washington, DC: Gallaudet, Pre-College Programs. (B)

Fitz-Gerald, M., & Fitz-Gerald, D.R. (Eds.). (1985). *Viewpoints: Sex education and deafness.* Washington, DC: Gallaudet, Pre-College Programs. (A)

Fitz-Gerald, D., Fitz-Gerald, M., Wilson, P., & Alter, J. (1986). *Starting at home: A family - centered approach to the prevention of teenage pregnancy.* Washington, DC: Gallaudet, Pre-College Programs. (B for Parent Resource Book; B for Trainer Manual)

Kroll, K., & Klein, E. (1992). *Enabling romance: A guide to love, sex, and relationships for disabled people (and the people who care about them).* New York: Crown. (B)

McDougall, J., & Hoffman, B. (1983). *Human development and reproductive health for the hearing impaired population.* St. Paul, MN: St. Paul Ramsey Medical Center-HIHW. (Five videos are in this series: Human Sexuality, Human Reproduction, Contraception, PAP/Pelvic Exam, and Breast Exam. Each video is $100; the entire series is $400.)

Minkin, M., & Rosen-Ritt, L. (1991). *Signs for sexuality: A resource manual for deaf and hard of hearing individuals, their families, and professionals.* (2nd ed.). Seattle, WA: Planned Parenthood of Seattle-King County. (C)

O'Day, B. (1983). *A resource guide for signs for sexual assault.* St. Paul: Minnesota State Department of Corrections. (ERIC Document Reproduction Service No. ED 277 213)

Shaman, E. (1985). *Choices: A sexual assault prevention workbook for persons who are deaf and hard of hearing.* Seattle: Seattle Rape Relief Crisis Center. (A)

CHRONIC ILLNESS

Greydamus, D.E., Gunther, M.S., Demarest, D.S., & Sears, J.M. (1990). Sexuality and the chronically ill adolescent. In M. Sugar (Ed.), *Atypical adolescence and sexuality* (pp. 147-157). New York: W.W. Norton. (C)

Kroll, K., & Klein, E. (1992). *Enabling romance: A guide to love, sex, and relationships for disabled people (and the people who care about them).* New York: Crown. (B)

National Center for Youth with Disabilities. (1991). *Issues in sexuality for adolescents with chronic illnesses and disabilities.* Minneapolis: Author. (A)

Schover, L.R., & Jensen, S.B. (1988). *Sexuality and chronic illness: A comprehensive approach.* New York: Guilford. (C)

Woodhead, J.C., & Murph, J.R. (1985, September). Influence of chronic illness and disability on adolescent sexual development. *Seminars in Adolescent Medicine, 1*(3), 171-176.

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FOSTERING RELATIONSHIPS: SUGGESTIONS FOR YOUNG ADULTS

This article is written expressly for young adults with disabilities. When the word "you" is used, it refers to *you*, the young adult with a disability.

You probably have been talking with your parents and others about the human body and the changes taking place in you physically and emotionally. You've probably also talked about what it means to have an adult relationship. Perhaps you wonder what your future will hold. Will you ever have an adult relationship — a boyfriend or girlfriend, a lover, a spouse? How will you meet this person? What will you talk about? What will you say about your disability? Will your disability distract the other person from seeing you for the whole and unique person you are? What can you do to foster a relationship and help it grow into something strong and meaningful to you both?

This article presents some ideas you may find helpful when you try to develop meaningful connections with others. Most of these ideas come directly from individuals with disabilities, including paraplegia, quadriplegia, spinal cord injuries, paralysis, polio, multiple sclerosis, and others. There are many common threads running through their stories (which are published in the books listed below). They speak of their experiences, hopes, wishes, failures, and successes as adults and loving human beings.

Here are some of their ideas about relationships, selfhood, disability, love, sexuality, friendship, patience, hope, and fulfillment.

➥ *Don't ever believe that no one will love you because you have a disability.* All the personal stories told in the books below give testimony to the fact that people with disabilities can both love and be loved. In these stories, the disability was not an obstacle to the love either partner felt. What mattered most for these people was that their relationships were based upon friendship, trust, laughter, and respect — all of which combined to spark and maintain their love. The disability only needed to be taken into consideration when the two people considered how to *make* love.

➥ *Don't build your life in search of romance.* Involve yourself in a variety of activities, such as work, community projects, and recreation. These activities will give you the opportunity to meet people. They will also help you grow as a person and avoid boredom and loneliness.

➥ *Be a friend first.* Don't rush — or be rushed — to be sexually intimate. A relationship is fostered through being a good listener and companion, a person who genuinely cares about others. Share activities and ideas. Romance can grow out of such solid ground.

➥ *Keep up on current events.* Being able to discuss a variety of topics can help conversations flow.

➥ *Be patient in your search for connection with others.* Relationships take time to develop. They cannot be forced. Don't settle for the first person who expresses an interest in you as a woman or a man, unless you are also interested in that person! Look for the person who suits you and appreciates you for who and what you are — disability included. That person is out there.

➥ *Be open about your disability.* Bring it up yourself, if you need to. Be prepared to answer questions. This is particularly true if you are interested in developing a relationship with a nondisabled person. Don't complain too much about your disability, though. Be positive and matter-of-fact. Relationships endure because they are based on openness, trust, and sharing.

➥ *Regardless of your disability, lovemaking is possible.* So is pleasure, for both you and your partner. You may need to be creative and flexible about how you make love. Certain techniques may be impossible for you, and you will need to develop your own techniques. Open and frank discussion between you and your partner is the key to solving whatever unique considerations your disability presents. Between loving and trusting partners, however, mutual pleasure and fulfillment are possible.

> ***I think that the harder someone tries to directly focus on finding social, romantic, or sexual partners, the more difficult it becomes. I would advise any disabled person to balance out their life and become actively involved in work, community projects, recreation, and other activities that involve platonic relationships. Then, make a conscious effort to become interested in the people you come in contact with. Opportunities for social contact will be a natural outgrowth of these activities. Concentrate on being a friend first. The romantic part will follow by itself. The same thing holds true whether you're disabled or not.*** (Lois, in Kroll & Klein, 1992, p. 30)

Resources

Kroll, K., & Klein, E.L. (1992). *Enabling romance: A guide to love, sex, and relationships for the disabled (and the people who care about them).* New York: Crown. **(B)**

Weiner, F. (Ed.). (1986). *No apologies.* New York: St. Martin's Press. **(B)**

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SPECIAL ISSUES

This final article looks at four issues that warrant special consideration from parents and professionals providing education about sexuality to children and youth with disabilities. These issues are:

- Sexual orientation;
- Reproduction and birth control;
- Protection against sexually transmitted diseases; and
- Protection against sexual exploitation and abuse.

Sexual Orientation

Sexual orientation refers to whether a person is heterosexual, bisexual, or homosexual. This section presents several basic facts about sexual orientation that may be of help to parents and professionals.

"Because sexual orientation is something that a person has, rather than something a person chooses, parents and professionals should be aware that strong, emotional messages against homosexuality or bixsexuality will not change the orientation a youth has."

First, it is not uncommon for children of the same gender to play "show me" games with one another. This is a normal part of development, for as children grow, their curiosity about their bodies grows as well. Experts caution parents against overreacting to this type of exploration, which often has much more to do with normal curiosity and with the availability and security of same-sexed friends than with homosexuality per se (Calderone & Johnson, 1990).

Researchers do not know what causes a person to have one sexual orientation versus another. Theories about what determines sexual orientation include factors such as genetics, prenatal influences, socio-cultural influence, and/or psychosocial factors (National Guidelines Task Force, 1991, p. 15). Parents may find it useful to realize that, in spite of the controversies that surround homosexuality and bisexuality, sexual orientation is not something that a person can change. When discussing their own social-sexual development, for example, gay men and women seem to report two basic types of personal stories. Many individuals report that they "always knew" what their sexual orientation was, from adolescence on and sometimes before. In contrast, others struggled for years trying to live up to society's expectations of heterosexuality. The realization that their sexual orientation was not heterosexual but, rather, homosexual was a gradual one ending in the awareness that they would not be able to bring their internal feelings into line with what society, their parents, their religion, or their culture wanted them to be.

Because sexual orientation is something that a person has, rather than something a person chooses, parents and professionals should be aware that strong, emotional messages against homosexuality or bixsexuality will not change the orientation a youth has. Such messages can — and do — create an impossible situation for the young person who feels one way but who is expected to feel and act another way. Thus, if you suspect that your young person is struggling with his or her own sexual orientation, you may want to:

- Read some of the books listed in the resource section below and familiarize yourself with the range of thinking and research on homosexuality, bisexuality, and heterosexuality;
- Consider carefully the messages you send your young person about homosexuality or bisexuality, for hostile, negative signals can do a great deal of harm to a person genuinely seeking to clarify sexual orientation;
- Share some of the books listed below with your young person;
- Be open to discussion with your child. Should your child tell you that he or she is homosexual or bisexual, don't withdraw your love and support; and
- Seek outside assistance (e.g., counseling, or call the National Federation of Parents and Friends of Lesbians and Gays, Inc.) if you are having difficulties accepting your child's sexual orientation.

References on Sexual Orientation

Calderone, M.S., & Johnson, E.W. (1990). *The family book about sexuality* (rev.ed.) New York: Harper Collins. (A)

National Guidelines Task Force. (1991). *Guidelines for comprehensive sexuality education: Kindergarten - 12th grade*. New York: Sex Information and Education Council of the U.S. (A)

Resources on Sexual Orientation

Alyson, S. (1991). *Young, gay and proud*. Boston: Alyson Publications. (A)

Anderson, D. (1990). Homosexuality in adolescence. In M. Sugar (Ed.), *Atypical adolescence and sexuality* (pp. 181-200). New York: W.W. Norton. (C)

Bozett, F.W., & Sussman, M.B. (Eds.). (1990). *Homosexuality and family relations*. New York: Harrington Park. (B)

Fairchild, B., & Hayward, N. (1989). *Now that you know: What every parent should know about homosexuality* (rev.ed.). San Diego: Harcourt Brace Jovanovich. (A)

Herdt, G. (Ed.). (1989). *Gay and lesbian youth*. New York: Haworth Press. (B)

Hetrick, E.S., & Martin, A.D. (1987). Development issues and their resolution for gay and lesbian adolescents. In E. Coleman (Ed.), *Integrated identity for gay men and lesbians*. New York: Harrington Park. (B)

Hidalgo, H., Peterson, T.L., & Woodman, N.J. (1985). *Lesbian and gay issues: A resource manual for social workers*. Silver Spring, MD: National Association of Social Workers. (B)

Savin-Williams, R.C. (1990). *Gay and lesbian youth: Expressions of identity*. New York: Hemisphere. (C)

Serving lesbian and gay youth. (1991, Spring/Summer). *Focal Point, 5*(2), 1-12. (A)

Sex Information and Education Council of the U.S. (1991). *Gay male and lesbian sexuality and issues: A SIECUS annotated bibliography of books for professionals and consumers*. New York: Author. (A)

Whitlock, K. (1989). *Bridges of respect: Creating support for lesbian and gay youth* (2nd ed.). Philadelphia: American Friends Service Committee. (A)

Reproduction and Birth Control

Any education about the development and expression of sexuality must include information about reproduction, the responsibilities of child-bearing, and how to protect oneself against unwanted pregnancy. (Protection against sexually transmitted diseases is a related issue of great importance and is discussed as the next SPECIAL ISSUE).

While there are disabilities that make it difficult or impossible for an individual to become pregnant or to impregnate another, most individuals with disabilities can have children and, therefore, need to understand the basics of reproduction and how pregnancy occurs. Parents and professionals can refer to the resources listed in previous sections of this ***NEWS DIGEST*** for books, pamphlets, and videos that can be useful in guiding discussions with young people with disabilities. (See in particular the resources listed in "Teaching Children and Youth about Sexuality" and "How Particular Disabilities Affect Sexuality and Sexuality Education.") Remember that discussing the basics of reproduction and pregnancy may require adapting materials or the presentation of information to the particular learning characteristics of the young person.

> ***Because all methods of contraception require forethought and commitment, and because the choice will vary according to disability, it is important to seek knowledgeable counseling about birth control.*** **(Kroll & Klein, 1992, p. 74)**

Comprehensive sexuality education does not end with providing information about how babies are conceived. It also involves providing information about the responsibilities of child-bearing and the importance of delaying sexual intercourse until the young person is mature enough emotionally to deal with its many responsibilities and consequences. To the extent that this can be done successfully, information about the various methods of birth control (natural, condom, IUD, pill, diaphragm, etc.) can play an important part in helping the person prevent unwanted pregnancies when sexual intercourse is finally chosen. In some families, birth control may be controversial, given personal, cultural, or religious beliefs. Yet, the decision to have children and *when* to have children is very much a personal one. Many individuals with disabilities will want to have children. Others may choose not to. Still others may be undecided or have specific concerns such as the possibility that their disability may be passed on genetically to offspring. Information on birth control and family planning is, therefore, essential for young people with disabilities to make responsible decisions about sexual health and behavior.

> ***"Information about birth control and family planning is...essential for young people with disabilities to make responsible decisions about sexual health and behavior."***

It is important to realize that some forms of birth control may be suitable for a person with a certain disability, while other forms may not. For example, young women who have difficulty with impulsivity, memory, or with understanding basic concepts may have difficulty understanding and using the rhythm method. Remembering to take a birth control pill every day would also be difficult, making both of these methods ineffective means of controlling against unwanted pregnancy. An alternate method of birth control, such as a time-released implant in the arm (known as NORPLANT), might be indicated. Similarly, for many youth with disabilities, learning to use a particular birth control method properly may involve more than just reading about the method or talking with their parents or doctor. For example, learning how to use a condom may require more than a simple instruction such as "you put it on." Some demonstration and practice may be needed before the person knows how to use the method effectively. It may be useful for parents to talk with the family physician about methods of birth control, and how suitable each method is when the young person's disability is taken into consideration.

Sterilization might be considered as an effective and pragmatic birth control option for some individuals with disabilities, particularly those who do not wish to

> ***I want to raise my own children, probably disabled, adopted. When I think about adopting children as a single parent, I think only about adopting disabled children...I feel that there are very few people around who see what I have been able to see, all the possibilities. You can take a kid and say, "You can be anything."*** **(Katherine C., in Weiner, 1986, p. 78)**

have children and those who are incapable of understanding the consequences of sexual activity or of assuming the responsibilities of parenthood. All the people involved in making such a decision should be aware that there are strict laws regarding sterilization. These laws vary from state to state, but in most cases, the person in question must give his or her informed consent to such a procedure. (This requirement is intended to protect individuals with disabilities against involuntary sterilization.) For some individuals who are severely disabled, however, it may be impossible to determine whether or not the consent is truly "informed." If sterilization is being considered as an option for the young person with disabilities, all persons involved in making such a decision will need to find out what the laws regarding sterilization are in their state.

Of course, many individuals with disabilities will want to have children at some point in their lives. For those who choose to have a child, conception may be more or less difficult, depending on the nature of the disability. Similarly, carrying and delivering the baby may present considerations unique to the disability. Many women with physical disabilities, for example, have difficulty finding an obstetrician who is willing to assume medical responsibility for a person who requires different treatment and consideration. Yet there are many stories of women who have successfully birthed and parented children in spite of such obstacles. To the young person looking into the future and the possibility of a family, it may be helpful to learn about the responsibilities involved in raising children and to meet, read about, or see on video individuals with disabilities who have successfully done so. These provide positive role models for young people who may feel that, because of their disability, they will never have children of their own.

For many, however, there may be concern that the disability might be inherited. Parents may wish to discuss genetic counseling with their child with a disability and with other children in the family as well. There are many materials available to facilitate discussion about this issue with family members. Genetic counseling is best obtained prior to pursuing parenthood. There are many agencies specializing in providing this sort of information; some are listed under ORGANIZATIONS at the end of this ***NEWS DIGEST***.

Listed below are resources that can help parents and professionals address with their children the issues of birth control, parenting, and genetic counseling. Remember that many of the resources listed at the end of the article entitled "Teaching Children and Youth About Sexuality" also include information about the basics of reproduction and birth control. You can also contact organizations such as Planned Parenthood for concise, easy-to-use pamphlets on reproduction and birth control. This information is vital to young people with disabilities and, as with all information about sexuality, needs to be presented in ways that take into consideration the particular individual and the disability he or she has.

Resources on Reproduction, Birth Control, and Genetic Counseling

Finger, A. (1990). *Past due: A story of disability, pregnancy, and birth*. Seattle, WA: Seal Press. **(B)**

Hakim-Elahi, E. (1982). Contraceptive of choice for disabled persons. *New York State Journal of Medicine, 82*(11), 1601-1608. **(A)**

Ince, S. (1987). *Genetic counseling*. White Plaines, NY: March of Dimes. **(A)**

Kroll, K., & Klein, E. (1992). *Enabling romance: A guide to love, sex, and relationships for disabled people (and the people who care for them)*. New York: Crown. **(B)**

March of Dimes Birth Defects Foundation. (n.d.). *Our genetic heritage*. White Plaines, NY: Author. **(C; This is a videotape explaining genes and heredity.)**

National Center for Education in Maternal and Child Health. (1991, January). *Understanding DNA testing: A basic guide for families*. Washington, DC: Author. **(A)**

Richards, D. (1986). Sterilization: Can parents decide? *Exceptional Parent, 16*(2), 40-41. **(A)**

Rodman, H., Lewis, S.H., & Griffiths, S.B. (1984). *The sexual rights of adolescents: Competence, vulnerability, and parental control*. New York: Columbia University Press. **(B)**

U.S. Department of Health and Human Services. (1980). *Learning together: A guide for families with genetic disorders* (DHHS Publication No. (HSA) 80-5131). Rockville, MD: Author.

Weiner, F. (Ed.) (1986). *No apologies*. New York: St. Martin's Press. **(B)**

Protection Against Sexually Transmitted Diseases

The topic of sexually transmitted diseases (STDs) is an extremely important one to discuss with young people. Accurate information about STDs is vital to help young people maintain sexual health and practice health-promoting behaviors. STDs include diseases such as gonorrhea, syphilis, HIV infection (which in advanced stages leads to AIDS), chlamydia, genital warts, and herpes. Most of these diseases can be cured with proper medical care. Exceptions to this are genital herpes, HIV infection, and AIDS, "although medications are now available which lessen symptoms and slow the development of the disease" (National Guidelines Task Force, 1991, p. 41).

Protecting oneself against sexually transmitted diseases (STDs) is a separate issue from protection against pregnancy. Youth with disabilities need to be informed that many methods of birth control do not provide protection against disease. They need to know what *does* offer protection and know how to obtain and use the method. They also need to know that abstinence from sexual intimacy is the surest way to avoid contracting an STD.

It is important to communicate accurate, up-to-date information (rather than use scare tactics) on the following topics:

- what sexually transmitted diseases are and what symptoms are associated with each one;
- how each STD is transmitted, including sexual behaviors that place the person at risk of contracting or transmitting the disease;
- myths about how a person can contract particular diseases;
- how each STD is treated medically, and those STDs that cannot be cured;
- health-promoting behaviors such as regular check-ups, breast and testicular self-exam, and identifying potential problems early.

Providing this information may be more or less difficult, depending on the nature of the person's disability. Individuals with mental retardation, for example, may have trouble understanding that a person can look healthy but still transmit a disease (Monat-Haller, 1992). It may be important to present information about STDs in very concrete terms, including pictures of what the various symptoms (e.g., lesions, blisters, etc.) look like. For individuals who have difficulty remembering information, it will be vital for parents and professionals to re-teach and re-emphasize the major points about disease prevention.

Many parents and professionals may need to inform themselves fully about these diseases before talking with young people with disabilities. The resources listed below are a starting point of gathering needed information about HIV/AIDS. Publishers listed at the end of this ***NEWS DIGEST*** (those marked with an asterisk) can provide low-cost pamphlets on the subject of HIV/AIDS, as well as the other STDs.

References on Sexually Transmitted Diseases

National Guidelines Task Force. (1991). *Guidelines for comprehensive sexuality education: Kindergarten - 12th grade.* New York: Sex Information and Education Council of the U.S. **(A)**

Monat-Haller, R.K. (1992). *Understanding and expressing sexuality: Responsible choices for individuals with developmental disabilities.* Baltimore, MD: Paul H. Brookes. **(B)**

Resources on Sexually Transmitted Diseases

Center for Population Options. (1989, September). *Adolescents, AIDS, and HIV: Resources for educators.* Washington, DC: Author. **(A)**

Crocker, A.C., Cohen, H.J., & Kastner, T.A. (1992). *HIV infection and developmental disabilities: A resource for service providers.* Baltimore, MD: Paul H. Brookes. **(C)**

Lindemann, J. (1990). *SAFE: An HIV/AIDS curriculum for individuals with MR/DD.* Portland, OR: Oregon Health Sciences University. **(D)**

National Sexually Transmitted Diseases Hotline: 1-800-227-8922.

National AIDS Hotline: 1-800-342-AIDS; 1-800-243-7889 (TDD).

Quackenbush, M., Nelson, M., & Clark, K. (1988). *The AIDS challenge: Prevention education for young people.* Santa Cruz, CA: Network/ETR Associates. **(B)**

Sex Information and Education Council of the U.S. (1989). *How to talk to your children about AIDS* (rev. ed.). New York: Author. **(A, also available in Spanish)**

Sex Information and Education Council of the U.S. (1990). *Communication strategies for HIV/AIDS and sexuality: A workshop for mental health and health professionals. A SIECUS training manual.* New York: Author. **(A)**

Sex Information and Education Council of the U.S. (1990). *Performance standards and checklist: For the evaluation and development of school HIV/AIDS education curricula for adolescents.* New York: Author. **(A)**

Sex Information and Education Council of the U.S. (1991). *Children, adolescents and HIV/AIDS education: A SIECUS annotated bibliography.* New York: Author. **(A)**

Young Adult Institute (producer). (1987). *AIDS: Training people with disabilities to better protect themselves.* New York: Young Adult Institute. **(C, to rent; E, to buy)**

What everyone should know about STDs. South Deerfield, MA: Channing L. Bete. **(A)**

Sexual Exploitation

One of the greatest fears of parents and caregivers is that their child with a disability will be sexually exploited. A number of factors may make individuals with disabilities more susceptible to sexual exploitation or abuse than their peers without disabilities. Rosen (1984) has identified several of these factors, which include:

- Physical limitations that make self-defense difficult;
- Cognitive limitations that make it difficult for the person to determine if a situation is safe or dangerous;
- Vulnerability to suggestion, because of limited knowledge of sexuality and human relations, including public and private behavior;
- Lack of information about exploitation and what to do if someone attempts to victimize them;
- Impulsivity, low self-esteem, and poor decision-making skills; and
- Lack of social opportunities that results in loneliness and vulnerability.

The fact that many individuals with disabilities are vulnerable to sexual exploitation makes it all the more imperative for parents and caregivers to address this issue with their child with a disability. Many child abuse prevention programs teach children to identify sexual abuse based upon the concept of "good touch" and "bad touch." Recently, this approach has raised concern among many professionals, for a number of reasons (see Krivacska, 1991). Perhaps the most critical concern is that, from a developmental perspective, young children are not necessarily capable of interpreting with accuracy the distinctions between a good and bad touch. Although most children lack understanding of appropriate expressions of sexuality, they must nonetheless make distinctions about inappropriate expressions.

Because young children (preschoolers and early elementary school children) are not cognitively, emotionally, or socially able to protect themselves against sexual exploitation or abuse, there are a number of steps that parents and professionals can take to help protect children. These include:

- Closely supervising the whereabouts and activities of children;
- Carefully scrutinizing the backgrounds and references of daycare providers and other caregivers;
- Being informed about sexual abuse, including knowing what physical and behavioral signs a child may show if abuse has occurred; and
- Distinguishing between teaching the child to be polite (e.g., saying hello to adults) versus compliant (e.g., requiring the child to kiss or be kissed by relatives, friends, or acquaintances when the child does not want to do so).

"If one must teach children about sexual abuse, one must first teach them, in an age-appropriate manner, about sexuality and healthy, appropriate forms of sexual expression."

Closely supervising young children (and older children as well) does *not* mean that parents or professionals should strictly limit children's activities (i.e., deny opportunities to participate in play groups, social groups, or community activities). Shielding persons with disabilities from the outside world may limit their contact with strangers, but it will not protect them from exploitation by friends, family members, or caregivers. Parents need to be aware that, in most cases, the abuser is someone the child knows.

There is also concern that young children may be receiving their first messages about sexuality in the negative, frightening terms associated with discussing sexual abuse. What impact this has upon the later development of healthy sexuality is unknown. Parents may need to consider the value of first providing information about the "healthy role sexuality plays in the human life cycle" (Krivacska, 1991, p. 3). "If one must teach children about sexual abuse, one must first teach them, in an age-appropriate manner, about sexuality and healthy, appropriate forms of sexual expression" (p. 6).

Once a foundation of understanding has been laid in terms that are positive about sexuality, then information about identifying, avoiding, and reporting sexual abuse can be given to children with disabilities. Beyond that, "the strongest protection against...sexual exploitation is an ongoing training program emphasizing self-reliance" (Gardner, 1986, p. 58). Building self-reliance includes:

- Telling children that they have the right to say "no" to touches or behaviors that hurt or make them uncomfortable. (Children should also know there are a few exceptions to this rule, such as getting a shot from the doctor.)
- Teaching children decision-making and self-advocacy skills, which provide a good foundation for saying "no."
- Letting children know that they should always tell someone when another person attempts to victimize them or when a situation makes them feel uncomfortable.

Listed below are resources that can help parents and professionals approach the issue of sexual exploitation and its prevention. Most of these resources include materials that can be used to teach children and youth with disabilities what sexual exploitation is and how to protect themselves from becoming a victim. Additional resources may be available by contacting some of the organizations listed at the end of this *NEWS DIGEST*, particularly those publishing pamphlets, books, and videos about sexuality.

References on Sexual Exploitation

Gardner, N.E.S. (1986). Sexuality. In J.A. Summers (Ed.), *The right to grow up: An introduction to adults with developmental disabilities* (pp. 45-66). Baltimore, MD: Paul H. Brookes. (This book has gone out of print but may be available through your public library.)

Krivacska, J.J. (1991, August/September). Child sexual abuse prevention programs: The need for childhood sexuality education. *SIECUS Report*, 19(6), 1-7. (A)

Rosen, M. (1984). *Sexual exploitation: A community problem.* Walnut Creek, CA: Planned Parenthood Association of Shasta/Diablo. (This book has gone out of print but may be available through your public library.)

Resources on Sexual Exploitation

Baird, K., & Kile, M.J. (1986). *Body rights: A DUSO approach to preventing sexual abuse of children.* Circle Pines, MN: American Guidance Service. (B)

Champagne, M., & Walker-Hirch, L. (1989). *Circles II: Stop abuse.* Santa Barbara, CA: James Stanfield. (F)

Child sexual abuse: A solution. (1986). Santa Barbara, CA: James Stanfield. (This 6-part program is available in filmstrip or video format and contains parts for children aged preschool to grade 6, for teachers and administrators, and for parents.) (F)

Girard, L.W. (1984). *My body is private.* Niles, IL: Albert Whitman & Company. (B)

Jessie. (1991). *Please tell! A child's story about sexual abuse.* Center City, MN: Hazelden. (A)

Kent Public Schools. (1985). *Self-protection for the handicapped: A curriculum designed to teach handicapped persons to avoid exploitation.* Seattle: Author. (ERIC Document Reproduction Service No. ED 263 705).

Nelson, M., & Clark, K. (1986). *The educator's guide to preventing child sexual abuse.* Santa Cruz, CA: Network. (B)

Planned Parenthood of Cincinnati. (producer). *Sexual abuse prevention: Five safety rules for persons who are mentally handicapped.* Cincinnati: Author. (This is a 30-minute video.) (E)

Seattle Rape Relief Developmental Disabilities Project. (1991). *The Project Action curriculum: Sexual assault awareness for people with disabilities.* Seattle: Author. (E)

Sobsey, R. (1991). *Disability, sexuality, and abuse: Annotated bibliography.* Baltimore, MD: Paul H. Brookes. (B)

Conclusion

This ***NEWS DIGEST*** has focused upon sexuality and sexuality education for children and youth with disabilities. While the issue of sexuality is often difficult for parents and professionals to discuss with children and youth, it is also one which is highly important to address in an open, frank, and matter-of-fact manner. Yet, sexuality education is not something that is accomplished in a limited number of lessons parents deliver; it is a life-long process of learning about ourselves and growing as social and sexual beings. Because children and youth with disabilities will mature and one day be adults functioning within the community, they have a right to be fully and accurately informed about what sexuality means, what responsibilities it involves, and what unique pleasures, joys, and pain this aspect to identity can bring. The special needs of individuals with disabilities must be taken into consideration when parents and professionals present information on attitudes, values, behaviors, and facts about social skills and sexuality. The resource lists in each article in this ***NEWS DIGEST*** will hopefully help parents and professionals meet the challenge of preparing young people with disabilities to make responsible decisions, form enriching and lasting relationships with others, and experience the full dimensions of what it means to be alive.

> ***You are a human being living in the society of human beings. This entails responsibility, provides opportunity, defines dignity, and denotes promise.*** **(William R., in Weiner, 1986, p. 8)**

References

Weiner, F. (Ed.) (1986). *No apologies.* New York: St. Martin's Press. (B)

Note: The quotations from Weiner (1986) appearing throughout this ***NEWS DIGEST*** are copyrighted 1986 by Florence Weiner. From the book *No Apologies* and reprinted with permission from St. Martin's Press, Inc., New York, NY. ***NICHCY*** thanks St. Martin's Press for its generous permission to reprint this material.

FYI: Information Resources from *NICHCY*'s Database

The publications and organizations listed below, as well as the resources listed throughout this ***NEWS DIGEST***, are only a few of the many that can provide information and services to parents, professionals, and individuals with disabilities about sexuality and sexuality education. Additional support is also available from state and local parent groups, as well as from state and local affiliates of many major disability organizations. Please note that these addresses are subject to change without prior notice. If you experience difficulty in locating an organization, please contact ***NICHCY***.

If you know of a group which is providing information about sexuality and sexuality education, particularly for individuals with disabilities, please send this information to NICHCY for our resource collection. We will appreciate this information and will share it with other families and professionals who request it.

Publishers: Books and Videos

The publishers listed below are only some of the many that provide information about sexuality and sexuality education. We present this list of names, addresses, and telephone numbers to help readers obtain the resources listed in this ***NEWS DIGEST***.

Note: We have placed an asterisk (*) next to the names of publishers that specialize in producing this type of information. Readers may find it useful to contact these publishers in particular and ask for a catalogue of their products. The catalogues will contain descriptions of pamphlets, books, and videos available, and will include resources not listed in this ***NEWS DIGEST***. Readers can then choose the ones that best fit their interests and needs.

Active Parenting, Inc., 810 Franklin Court, Suite B, Marietta, GA 30067. Telephone: 1-800-825-0060.

ADIS Press - Contact F.A. Davis Company, 1915 Arch Street, Philadelphia, PA 19103-9954. Telephone: (215) 568-2270.

Albert Whitman & Company, 6340 Oakton Street, Morton Grove, IL 60053. Telephone: 1-800-255-7675 or (708) 647-1355.

Alyson Publications, Contact Inbrook Distribution Company, P.O. Box 120470, East Haven, CT 06512. Telephone: 1-800-253-3605.

American Academy of Pediatrics, Committee on Adolescence, Division of Publications, 131 Northwest Point Boulevard, P.O. Box 927, Elk Grove Village, IL 60009-0927. Telephone: 1-800-433-9016.

American Film & Video, 8901 Walden Road, Silver Spring, MD 20901. Telephone: 1-800-78-VIDEO.

American Friends Service Committee, 1501 Cherry Street, Philadelphia, PA 19102. Telephone: (215) 241-7048.

American Guidance Service, Publishers' Building, P.O. Box 99, Circle Pines, MN 55014-1796. Telephone: 1-800-328-2560. In MN, call 1-800-247-5053.

Bantam Books, 666 Fifth Avenue, New York, NY 10103. Telephone: 1-800-223-6834.

Center for Early Adolescence, University of North Carolina at Chapel Hill, Suite 211, Carr Mill Mall, Carrboro, NC 27510. Telephone: (919) 966-1148.

Center for Population Options, 1025 Vermont Avenue N.W., Washington, DC 20005. Telephone: (202) 347-5700.

Center on Human Policy, School of Education, Syracuse University, 200 Huntington Hall, 2nd Floor, Syracuse, NY 13244-2340. Telephone: (315) 443-3851.

***Channing L. Bete Company**, 200 State Road, South Deerfield, MA 01373. Telephone: (413) 665-7611.

Charles C. Thomas, 2600 S. First Street, Springfield, IL 62794-9265. Telephone: (217) 789-8980.

College-Hill Press - Contact Pro-Ed, 8700 Shoal Creek Boulevard, Austin, TX 78758. Telephone: (512) 451-3246.

Columbia University Press, 136 S. Broadway, Irvington-on-Hudson, NY 10533. Telephone: (914) 591-9111.

Council for Exceptional Children, Division on Mental Retardation, 1920 Association Drive, Reston, VA 22091-1589. Telephone: (703) 620-3660.

Crown Publishers, c/o Harmony Books Division, 201 East 50th Street, New York, NY 10022. Telephone: (212) 751-2600.

Ednick Communications - Contact Pro-Ed, 8700 Shoal Creek Boulevard, Austin, TX 78758. Telephone: (512) 451-3246.

Edwin Mellen Press, P.O. Box 450, Lewiston, NY 14092. Telephone: (716) 754-2788.

Family Life Education Associates, P.O. Box 7466, Richmond, VA 23221. Telephone: (804) 264-5929.

Federation for Children with Special Needs and the Center on Human Policy, the Technical Assistance for Parent Programs (TAPP) Project, 312 Stuart Street, Second Floor, Boston, MA 02116. Telephone: (617) 482-2915.

Gallaudet University, Bookstore, 800 Florida Avenue N.E., B20E, Washington, DC 20002-3695. Telephone: (202) 651-5380.

Grune and Stratton, c/o Prentice-Hall, Attention: Mail Order Sales, 200 Old Tappan Road, Old Tappan, NJ 07675. Telephone: 1-800-223-1360.

Guilford Press, 72 Spring Street, New York, NY 10012. Telephone: 1-800-365-7006.

Harcourt Brace Jovanovich, 465 S. Lincoln Drive, Troy, MO 63379. Telephone: 1-800-543-1918.

Harper Collins, Keystone Industrial Park, Reeves & Monahan, Scranton, PA 18512. Telephone: 1-800-331-3761.

Harrington Park Press, 10 Alice Street, Binghamton, NY 13904-1580. Telephone: 1-800-342-9678.

Harvard University Press, Attention: Customer Service, 79 Garden Street, Cambridge, MA 02138. Telephone: (617) 495-2600.

Haworth Press, 10 Alice Street, Binghamton, NY 13904-1580. Telephone: 1-800-342-9678.

Hazelden, P.O. Box 176, Center City, MN 55012-0176. Telephone: 1-800-328-9000.

Hemisphere Publishing Corporation, 1900 Frost Road, Suite 101, Bristol, PA 19007. Telephone: 1-800-821-8312.

International Diagnostic Services, Inc., P.O. Box 389, Worthington, OH 43085. Telephone: (614) 885-2323.

Interstate Research Associates - Contact ***NICHCY***, P.O. Box 1492, Washington, DC 20013. Telephone: 1-800-999-5599.

***James Stanfield Publishing Company**, P.O. Box 41058, Santa Barbara, CA 93140. Telephone: 1-800-421-6534.

Johns Hopkins University Press, 701 West 40th Street, Baltimore, MD 21211. Telephone: 1-800-537-5487.

MacMillan, Front & Brown Streets, Riverside, NJ 08075. Telephone: 1-800-257-5755.

March of Dimes, 1275 Mamaroneck Avenue, White Plaines, NY 10605. Telephone: (914) 428-7100.

National Association of School Psychologists, Publications, 8455 Colesville Road, Silver Spring, MD 20910. Telephone: (301) 608-0500.

National Association of Social Workers, P.O. Box 92180, Washington, DC 20090-2180. Telephone: 1-800-752-3590.

National Center for Education in Maternal and Child Health, 38th and R Street, N.W., Washington, DC 20057. Telephone: (202) 625-8400.

National Center for Youth with Disabilities, University of Minnesota, Box 721 - UMHC, Harvard Street at East River Road, Minneapolis, MN 55455. Telephone: 1-800-333-6293.

National Down Syndrome Society, 666 Broadway, New York, NY 10012. Telephone: 1-800-221-4602.

National Federation of the Blind, 1800 Johnson Street, Baltimore, MD 21230. Telephone: (301) 659-9314.

***Network Publishing**, Division of ETR Associates, P.O. Box 1830, Santa Cruz, CA 95061-1830. Telephone: (408) 438-4060.

Oregon Health Sciences University, Child Development and Rehabilitation Center, P.O. Box 574, Portland, OR 97207. Telephone: (503) 494-7522.

Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285-0624. Telephone: 1-800-638-3775.

People Building Institute, 330 Village Circle, Sheldon, IA 51201. Telephone: (712) 324-4873.

Pergamon Press, c/o MacMillan, Front & Brown Streets, Riverside, NJ 08075. Telephone: 1-800-257-5755.

***Planned Parenthood Federation of America**, Marketing Department, 810 Seventh Avenue, New York, NY 10036. Telephone: (212) 819-9770. (This is the central headquarters for Planned Parenthood.)

***Planned Parenthood of Alameda/San Francisco**, 815 Eddy Street, Suite 300, Attention: Education Department, San Francisco, CA 94109. Telephone: (415) 441-7858.

Planned Parenthood of Cincinnati - The video listed with this publisher is available by contacting the Agency for Instructional Technology, Box A, Bloomington, IN 47402. Telephone: 1-800-457-4509.

Planned Parenthood of Humboldt County, 2316 Harrison Avenue, Eureka, CA 95501. Telephone: (707) 442-5709.

***Planned Parenthood of Minnesota**, The Resource Center, 1965 Ford Parkway, St. Paul, MN 55116. Telephone: (612) 698-2401.)

Planned Parenthood of Seattle-King County, Attention: Bookstore, 2211 East Madison, Seattle, WA 98112-5397.

Planned Parenthood of Shasta/Diablo, 1291 Oakland Boulevard, Walnut Creek, CA 94596. Telephone: (510) 935-4066.

Planned Parenthood of Southeastern Pennsylvania, The Resource Center, 1144 Locust Street, Philadelphia, PA 19107. Telephone: (215) 351-5560.

Plenum Publishing, 233 Spring Street, New York, NY 10013-1578. Telephone: 1-800-221-9369.

Pro-Ed, 8700 Shoal Creek Boulevard, Austin, TX 78758. Telephone: (512) 451-3246.

Research Press, 2612 North Mattis Avenue, Champaign, IL 61821. Telephone: (217) 352-3273.

Robert E. Krieger Publishing, P.O. Box 9542, Melbourne, FL 32902-9542. Telephone: (407) 724-9542.

R.R. Bowker, 121 Chanlon Road, New Providence, NJ 07974. Telephone: 1-800-521-8110.

Seal Press, 3131 Western Avenue, No. 410, Seattle, WA 98121-1028. Telephone: (206) 283-7844.

Seattle Rape Relief Crisis Center, 1905 S. Jackson, Seattle, WA. Telephone: (206) 325-5531.

Seattle Rape Relief Developmental Disabilities Project, 1905 S. Jackson, Seattle, WA 98144. Telephone: (206) 325-5531.

***Sex Information and Education Council of the U.S.** (SIECUS), 130 West 42nd Street, Suite 2500, New York, NY 10003. Telephone: (212) 819-9770.

Simon and Schuster, Order Processing Department, P.O. Box 11071, Des Moines, IA 50336-1071. Telephone: (515) 284-6751.

St. Martin's Press, 175 Fifth Avenue, New York, NY 10010. Telephone: 1-800-221-7945.

St. Paul Ramsey Medical Center-HIHW, 640 Jackson Street, St. Paul, MN 55101. Telephone: (612) 221-3569.

United Cerebral Palsy Associations, Inc., UCP/Lancaster County, 1811 Olde Homestead Lane, P.O. Box 10485, Lancaster, PA 17605-0485. Telephone: (717) 396-7965.

U.S. Department of Health and Human Services - Contact the Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402.

Vida Publishing, Primrose Lane/Highland Drive, P.O. Box 597, Mountville, PA 17554.

Volcano Press, P.O. Box 270, Volcano, CA 95689. Telephone: (209) 296-3445.

Walker Publishing, 720 Fifth Avenue, New York, NY 10019. Telephone: 1-800-289-25537.

W.W. Norton & Company, c/o National Book Company, 800 Keystone Industrial Park, Scranton, PA 18512-4601. Telephone: 1-800-223-2584.

***Young Adult Institute**, 460 West 34th Street, New York, NY 10001. Telephone: (212) 563-7474.

Journal Addresses

Note: When you call or write for a reprint of a journal article, make sure you give the complete reference (name of author, name of article, name of journal, and its volume and number).

Academic Therapy - Contact Pro-Ed, 8700 Shoal Creek Boulevard, Austin, TX 78758-6897. Telephone: (512) 451-3246. Ask for the journal department.

ASHA - Contact the American Speech-Language-Hearing Association, 10801 Rockville Pike, Rockville, MD 20852. Telephone: (301) 897-5700. Ask for Extension 218.

Churchill Forum - Contact Churchill Center for Learning Disabilities, Inc., 22 East 95th Street, New York, NY 10128. Telephone: (212) 722-0610.

Exceptional Parent - Contact 1170 Commonwealth Avenue, 3rd Floor, Boston, MA 02134-9942. Telephone: (617) 730-5800.

Focal Point - Contact Portland State University, Research and Training Center on Family Support and Children's Mental Health, Regional Research Institute for Human Services, P.O. Box 751, Portland, OR 97207-0751. Telephone: (503) 725-4040.

Journal of Learning Disabilities - Contact Pro-Ed, 8700 Shoal Creek Boulevard, Austin, TX 78758-6897. Telephone: (512) 451-3246. Ask for the journal department.

Journal of Visual Impairment and Blindness - Contact the American Foundation for the Blind, 15 West 16th Street, New York, NY 10011. Telephone: (212) 620-2149. Say that you would like to order a reprint of an article.

New York State Journal of Medicine - Contact the Medical Society of the State of New York, 420 Lakeville Road, Box 5404, Lake Success, NY 11042-1160. Telephone: (516) 488-6100.

Sexuality and Disability - Contact J. S. Canner & Company, Inc., 10 Charles Street, Needham Heights, MA 02194. Telephone: (617) 449-9103.

SIECUS Report - Contact SIECUS, 130 West 42nd Street, Suite 2500, New York, NY 10036. Telephone: (212) 819-9770.

Special Parent/Special Child - Contact Lindell Press, Inc., P.O. Box 462, South Salem, NY 10590.

Teaching Exceptional Children - Contact Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091-1589. Telephone: (703) 620-3660. Ask for Publications Department.

Volta Review - Contact Alexander Graham Bell Association for the Deaf, 3417 Volta Place N.W., Washington, DC 20007. Telephone: (202) 337-5220. Ask for Brooke Rigler, Managing Editor.

ORGANIZATIONS

The organizations listed below are only a few of the many that provide services and information about sexuality to families and professionals. Additional information may also be available from state and local parent groups and state and local affiliates of many major disability organizations.

When calling or writing an organization, it is always a good idea to be as specific as you can in stating your needs. For example, state the gender and age of your child, the disability he or she has, and any special needs or interests you have in making your request. This helps organizations provide you with information that is truly helpful and on target.

Genetics Counseling Organizations

Alliance of Genetic Support Groups - 1001 22nd Street N.W., Suite 800, Washington, DC 20037. Telephone: 1-800-336-GENE.

The Arc (formerly the Association for Retarded Citizens of the United States), 500 East Border Street, Suite 300, Arlington, TX 76010. Telephone: (817) 261-6003

Mid-Atlantic Regional Human Genetics Network (MARHGN) - University of Virginia School of Medicine, Division of Medical Genetics, Box 386, Charlottesville, VA 22908.

National Center for Education in Maternal and Child Health - 38th and R Streets N.W., Washington, DC 20057. Telephone: (202) 625-8400.

National Genetics Foundation - 555 West 57th Street, New York, N Y 10019. Telephone: (212) 586-5800.

National Society of Genetic Counselors - Clinical Genetics Center, Children's Hospital of Philadelphia, 34th and Civic Center Boulevard, Philadelphia, PA 19104. Telephone: (215) 596-9802.

Other Organizations

American Association of Sex Educators, Counselors, and Therapists (AASECT) - Suite 1717, Chicago, IL 60611-4067. Telephone: (312) 644-0828.

Coalition on Sexuality and Disability, Inc. - 122 East 23rd Street, New York, NY 10010. Telephone: (212) 242-3900.

March of Dimes Birth Defects Foundation - 1275 Mamaroneck Avenue, White Plaines, NY 10605. Telephone: (914) 428-7100.

National AIDS Hotline: 1-800-342-AIDS; 1-800-243-7889 (TDD); 1-800-344-7432 (Spanish).

National Sexually Transmitted Diseases Hotline: 1-800-227-8922.

National Center for Youth with Disabilities - University of Minnesota, Box 721 UMHC, Harvard Street at East River Road, Minneapolis, MN 55455. Telephone: 1-800-333-6293 and (612) 626-2825.

National Clearinghouse on Women and Girls with Disabilities - 1144 East 32nd Street, New York, NY 10016. Telephone: (212) 725-1803.

National Federation of Parents and Friends of Lesbians and Gays - 1012 14th Street, N.W., Suite 700, Washington, DC 20005. Telephone: (202) 638-4200.

National Rehabilitation Information Center (NARIC) - 8455 Colesville Road, Suite 935, Silver Spring, MD 20910-3319. Telephone: 1-800-34-NARIC; (301) 588-9284 (Local and TDD).

Networking Project for Disabled Women and Girls - YWCA/NYC, 610 Lexington Avenue, New York, NY 10022.

Sex Information and Education Council of the U.S. (SIECUS) - 130 West 42nd Street, Suite 2500, New York, NY 10003. Telephone: (212) 819-9770.

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